

Prostate Cancer™

U P D A T E

Conversations with Urologic Oncology Leaders
Bridging the Gap between Research and Patient Care

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SPECIAL ISSUE

*Clinicians with a Personal or
Family History of
Prostate Cancer:
A Roundtable Discussion*

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PURPOSE OF THIS ISSUE OF *PROSTATE CANCER UPDATE*

The purpose of Issue 5 of *Prostate Cancer Update* is to support these global objectives by offering the perspectives of clinicians with prostate cancer on these issues.

UPCOMING EDUCATIONAL EVENTS

2005 American Society of Clinical Oncology
Prostate Cancer Symposium:
February 17-19, 2005

Hyatt Grand Cypress
One Grand Cypress Blvd
Orlando, FL

Event website: www.asco.org/ac/1,1003,12-002665-00_18-0034689,00.asp

10th National Comprehensive Cancer Network
Annual Conference: March 16-20, 2005

Westin Diplomat
3555 South Ocean Drive,
Hollywood, FL

Event website: www.nccn.org/professionals/meetings/10thannual/default.asp

Challenging Cases in Urology February 24-26, 2005

Fountainbleau Hilton Hotel
Mami, FL

Contact phone: (770)-751-7332

41st American Society of Clinical Oncology
Annual Meeting: May 13-17, 2005

Orange County Convention Center
Orlando, FL

Event website: www.asco.org/ac/1,1003,12-002092,00.asp

2005 American Urological Association
Annual Meeting: May 21- 26, 2005

San Antonio, TX

Event website: www.aua2005.org/am05/?CFID=1463668&CFTOKEN=29660692

2005 American Society for Therapeutic
Radiology and Oncology Annual Meeting:
October 16-20, 2005

Denver, CO

Event website:
www.astro.org/annual_meeting/



Editor's Note

Visiting professors

Prior to my own experience, I didn't really understand what happens internally when you are diagnosed with prostate cancer. I have always tried to distance myself from my patients so that I could deal with their problems. When you have the disease, things are different.

— Jeffrey Deeths, MD

I would echo the visceral nature of being diagnosed with prostate cancer. For me, I felt a great sense of sadness and a feeling that things had changed. Even if you have 15 percent of one core, Gleason 3 + 3, things have changed. It is now part of your life, and you can't put the genie back in the bottle.

— Richard -, MD

Nobody knows what it's like to go through what their patients go through unless they've gone through it themselves. You can try to imagine it, but you can't.

— Alan Roberts, MD

Having been on the other side, one of the most powerful medicines is a sense of optimism from the person who's taking care of you, and not just sort of brainlessly patting you on the shoulder, but a true, reasoned and genuinely felt sense of optimism.

— Gustav Magrinat, MD

My first major educational foray outside the endless field of breast cancer began more than three years ago when I was unexpectedly contacted about the possibility of launching a new audio series on prostate cancer. Our previous audiences for many years had been medical oncologists, surgeons, and oncology nurses, but the prostate series would be for urologists and radiation oncologists... Sure, why not!

The prostate experience was deceiving at first — it looked easy, but wasn't. It took a couple of years to learn the subtleties of the research-to-practice issues involved in the urologic oncology culture. Along this very interesting path, three unusual experiences helped us discover that this disease was, in fact, unique.

As part of our CME needs assessment program, we regularly invite outstanding research leaders to participate in a visiting professor series. Physicians spend a day with our education team in Miami, where they present research data, answer questions and allow us to pick their well-developed brains. Toward the end of the day, we conduct many of the interviews you hear for our various audio series.

The visiting professorships in prostate cancer yielded some of the most personal and compelling interviews of my career, starting with the second one we hosted with urologist Paul Schellhammer.

Within the first few moments of chatting over a cup of coffee, Paul — in his gentle and humble manner — made it known that after a career of prostate cancer clinical research, he himself had been diagnosed with the disease. Much to my surprise, he was totally willing to share this experience with our national audience of physicians. After a lifetime of considering radical prostatectomy a relatively routine procedure, Paul developed a psoas abscess after his surgery. He also noted that just prior to our meeting, his PSA assay was persistently elevated, and he shared his thoughts with me about what steps he might take.

A storm of supportive emails from listeners followed this unplanned experience, and one year later, I again asked Paul to record an interview. At that time he was recovering from radiation therapy and complete androgen blockade. This interview again resulted in very positive feedback from our listeners.

The month after Paul's first visit to Miami, another unexpected discussion occurred. Judd Moul was visiting our shop for a long and very educational day. Judd — in his thoughtful, candid and very well-informed manner — shed a great deal of light on key controversial issues such as management of PSA relapse and watchful waiting for low-risk tumors. Toward the end of our conversation, he mentioned that his father-in-law died of prostate cancer about 10 years ago.

This was a painful experience for the entire family, and one that was particularly disturbing to Judd, who from the beginning, was constantly reassuring his loved ones that prostate cancer is usually an indolent and non-life-threatening disease. When his father-in-law died 36 months after first diagnosis, Judd believed he had "let his family down."

A third extraordinary visiting professorship occurred not too long after that. Radiation oncologist Colleen Lawton spent the day with our team reviewing prior, current and future RTOG trials. During the end-of-day interview, after discussing her many research activities in the management of locally advanced disease, Colleen casually commented, "and my Dad was actually treated for locally advanced prostate cancer."

I silently digested this for a few minutes and then asked her to tell the story, which included her father being treated with a regimen of androgen deprivation and radiation therapy that she had developed and tested in a randomized RTOG trial. One positive outcome of this experience for Colleen was that her prostate cancer patients could no longer think that, as a woman, she would have no idea what they were going through.

Being a scientific person who also believes in fate, I figured that these three extraordinary people had crossed our group's path for a reason and that perhaps it would be interesting and informative to gather them together with a group of other oncology peers who also had personal experiences with prostate cancer, and audio record the event.

Amazingly enough, this actually happened in Atlanta on October 7, 2004. In addition to the three visiting professors, we recruited 11 other physicians — mostly urologists, medical oncologists and radiation oncologists — to participate in this event. All except one had been diagnosed with prostate cancer, ranging from low-risk localized disease to PSA relapse to metastases. The “nonpatient” was a radiation oncologist, who very much wanted to talk about his father, who has experienced essentially no morbidity from metastatic disease, but is virtually housebound due to the adverse effects of androgen deprivation.

The clinical backgrounds of these physicians varied widely and included major research figures who run urology departments and multidisciplinary prostate cancer research programs, and a couple of retired docs who now do consults in post offices and at condo meetings.

One urologist and radical prostatectomy survivor is a self-described “country doctor” who treats mostly indigent people in a small town, while another panelist was a medical oncologist who was very pleased that he — unlike a couple of colleagues — chose to have laparoscopic rather than open prostatectomy. Another urologist learned by phone during rounds on two post-op prostatectomy patients that he had a very low-grade tumor. In spite of his knowledge of the disease and the favorable prognosis in this situation, he wouldn't buy clothes for six months after the diagnosis because he assumed he would soon die from the disease.

The group bonded relatively quickly and spent the day talking about the diagnosis, treatment — and in some cases, non-treatment — of prostate cancer, and how their perspectives changed after what was for all, a life-altering experience. The relatively unplanned and free-flowing discussion over about six hours was then edited into this special end-of-year issue.

I don't know what else to say except, stick the tape or CD in your car and see what you think.

— Neil Love, MD
NLove@ResearchToPractice.net

The initial reaction to the diagnosis of prostate cancer

DR SCHELLHAMMER: Although I should have known better, when I was diagnosed I began thinking that I would live perhaps three to five years.

It took a few weeks of seeing charts of patients who were five, 10 and more years out from their diagnosis to have a greater sense of security. Despite my knowledge base, initially my visceral reaction was significant.

DR LOVE: What kinds of things help people overcome those types of reactions?

DR SCHELLHAMMER: It takes a significant amount of physician interaction to provide patients assurance that even if the disease cannot be cured, it can be controlled for long periods of time.

That is, however, a difficult message to impart in a convincing manner without several interactions and a lot of reading on the part of the patient. It becomes a real subject of study, deliberation and interaction.

DR DEETHS: I had the same feelings when I was diagnosed seven years ago. I had a biopsy on a Friday, and because I was known at the hospital, the pathologist came in and read the slides on Saturday morning. I happened to be on call that weekend and was making rounds on two patients I had operated on for prostate cancer. I heard the diagnosis in the middle of my rounds and was devastated.

DR LOVE: How were you able to adapt to this situation and deal with it?

DR DEETHS: It takes time. It took me six months to a year to really come out of the doldrums. Before that I said

to myself, “I’m not going to buy any new shoes or clothes” because I didn’t think I would live long enough to need them.

DR LOVE: You told me that you had a Gleason 2+3 tumor. I’m sure that when you are taking care of men with low-grade tumors, you reassure them that they have an excellent prognosis. Did this experience change the way you view those men?

DR DEETHS: Prior to my own experience, I didn’t really understand what happens internally when you have the diagnosis of prostate cancer. I have always tried to distance myself from my patients so that I could deal with their problems. When you have the disease, things are different.

My doctor was one of my practice partners, and it was difficult, in a sense, because he knew what I knew about prostate cancer, the treatments and all the ramifications.

Also, I didn’t involve my wife in the decision-making because I knew what I wanted to do. That was a serious mistake because she didn’t feel like she was part of the experience. Spouses definitely need to be part of the experience all the way through, from the time of diagnosis.

RICHARD: I would echo the visceral nature of being diagnosed with prostate cancer. For me, I felt a great sense of sadness and a feeling that things had changed. Even if you have 15 percent of one core, Gleason 3+3, things have changed. It is now part of your life, and you can’t put the genie back in the bottle.

DR ROBERTS: I think we sometimes become very cavalier in how we treat other physicians. This may be a good learning experience for those of us who have to go on taking care of patients when we have prostate cancer.

When a physician finds out he has prostate cancer, I don't think he necessarily reacts any differently than anybody else. It reminds me of the fact that in my work, I deal with ethics and end-of-life issues, and when my mother was dying, I didn't know any more than anybody else about whether to put her on a vent or not.

The urologist who did my biopsy called my wife to tell her the results. My Gleason score was 9; my PSA had doubled in the previous year and I had a palpable lesion.

Maybe it was because I'm a physician and he thought this was okay for him to do, but when I arrived home, my wife was convinced that I only had a year to live.

DR LOVE: Your wife was told first?

DR ROBERTS: Yes, and I just think that we have to tell people these things a little differently than over the telephone.

DR LOVE: Is it common for people to be given a diagnosis over the phone?

DR MOUL: I don't know if this was an anomaly, but in my former practice in the military, we had patients coming in from quite a long distance and sometimes we were forced to give them a diagnosis over the phone.

I don't know how common that is in the "real world," but it always bothers me. I think with the growing shortage of urologists in this country, it may be happening more often.

Another fairly common decision we all face is whether to give a patient bad news on a Friday afternoon or wait until Monday morning.

DR LANGE: I believe that giving patients control over what and when they learn about their disease, whether it's a diagnosis or their recent PSA, is an issue.

Paul and I have talked many times about when we look up our PSA. Should we do it before or after we're going out for a big dinner or when our kid is getting married?

I think that rather than telling patients we'll call them, and then not being able to connect with them and having them experience anxiety, we could alleviate that stress using modern web-based methods.

This would give patients the power to learn when they wanted to, rather than when you're available. I think the idea that the physician is going to be the primary person to inform everybody, particularly if you have a busy practice, is unrealistic. We need to develop other methods whereby patients have more power over this.

I always tell patients who are about to undergo a biopsy, "If you have a diagnosis, it's not the end of the world." But it is humbling to experience that fear, in some cases receiving your first taste of your own mortality.

I have learned that even though I take prostate cancer somewhat lightly, because I know about autopsy cancer and the Pound paper, I remind patients that they are going to be okay and I do that early.

I often say, "You're going to be fine. This is not lung cancer in terms of the

frequency of mortality and its speed of mortality.”

RICHARD: Having a Gleason 3+3 tumor causes uncertainty. What does it mean? Is this really disease? Is this something that’s destined to be clinically significant? Does this need to be treated and will the treatment cause significant morbidity?

For the physician-patient, the sophisticated layperson and treating physicians, this is a very difficult issue. My surgeon was candid about the limitations of his knowledge about who needed to be treated.

Sixty percent of my practice is dedicated to breast oncology, and my experience with prostate cancer and the uncertainty I felt has certainly impacted the discussions I have regarding adjuvant therapy of breast cancer.

DR STUTZMAN: I had a biopsy in mid-December and received a diagnosis right away from my colleagues. Christmas is always a big time for my family, and I went through the holidays without telling them anything about my diagnosis. Finally, before everybody went home, I sat them down and

told them that I already had a surgery date. My wife has never forgiven me for that, and now when I have any problem, she says, “Are you lying to me?” I have told patients “Get your family involved,” because I learned personally that not involving them was the wrong thing to do.

DR LOVE: Why didn’t you tell your family?

DR STUTZMAN: I didn’t want to ruin their holidays.

DR MOUL: This is very moving to hear. I’m struck because urologists are always receiving criticism for overdiagnosing prostate cancer. I just heard these physicians, who scientifically recognize that Gleason 6 prostate cancer is probably not necessarily life threatening, yet they had the same emotions as a man with life-threatening prostate cancer. This blows me away.

Then, the question comes up: “Should we consider not even calling these tumors prostate cancer?” Would it change things if we considered it a precancerous state to avoid freaking out people with these favorable lesions?

Discussing treatment options for localized disease

RICHARD: I think most of us are in no shape to make treatment choices when we hear our diagnosis. Most of our patients are in no shape to make choices either.

When you go to the multidisciplinary clinic and hear the radiation oncologist, the medical oncologist and the urologist, you’re just like a patient. You are overwhelmed. You become almost amnesic hearing all that information. I think it takes time.

I’d like to think I was perfectly aware of the power of words before this experience, but after my diagnosis I became a lot more aware and realized how powerful words can be. Sometimes even casual comments can be devastating, insulting or demoralizing without being intended that way.

I was told by a well-known urologic oncologist who went through the spiel about conventional radical prostatectomy, “You will have a good chance

of retaining your sexual function but of course, you'll be shooting blanks." I knew at some intellectual level what he was talking about, but his words added to the overall misery of the experience.

We really have to be careful how we talk to people — the words we use and how we use them — because the message is different when you're receiving it at a visceral level.

DR MAGRINAT: My reaction to the diagnosis was different than what I heard today. I was almost relieved to have a prostatectomy because I had been thinking for years that I was going to develop the disease.

What really worried me were perhaps silly things: Should I tell my patients or not? Are people going to think differently about me because I have cancer? Are other doctors going to stop thinking of me as an invulnerable omniscient physician?

I decided to be very open. I told everyone everything from day one. I was surprised by my patients' reactions. They were so supportive, kind, caring and worried about me. I don't notice any change in the way my partners or colleagues treat me. They still overwhelm me with more patients than I want to see!

DR LAWTON: Because I am a woman, many of my patients say, "What could you possibly understand about what I'm going through?" I think telling patients about my dad's diagnosis — which he gave me permission to do — really helped me with prostate cancer patients in my practice.

My patients have been amazingly supportive and many ask me, "Oh, by the way, how's your dad?" My dad

has had a PSA recurrence and even when I tell them he's doing fine, they say, "Is he doing okay? Are you okay?" They're amazing.

DR FAGAN: I'm retired now and have been for a number of years, but I do a lot of consultations in the post office, grocery store and on the street corner. People come to me for information and guidance. Most of them know me and know that I had cancer. It's important to outline all the possibilities for people and tell them it's not necessarily the end of the world.

I was in total denial when I was diagnosed and for a long time afterward. I had a wonderful medical advocate — my wife. She's the one who pushed me to do the things that I needed to do because I really couldn't make the decisions myself.

I saw an oncologist who said to me, "If you were 50, we'd probably treat you a little more radically." Then, my wife said to him, "Look doctor, you're 50 years old. You could walk out on the street and get killed by a car, and my husband could live for 20 years." Eventually, I ended up with another oncologist who is treating me with experimental drugs, and I am very happy.

DR MOUL: One of the things that we, as urologists, have been criticized for in the past was being too aggressive in older individuals. How do we balance the issue of not practicing age discrimination versus over-treating a lot of patients? I think we probably need to be embracing watchful waiting a lot more for our patients with lower-risk disease; yet, it's not very popular. I was just wondering if any of the physicians here even considered watchful waiting.

DR DEETHS: I had a low-stage, low-grade cancer. As a surgeon, I didn't feel that watchful waiting was an option. This was seven years ago and at that time, PSAs and surgery were somewhat different than they are today.

I've always told my patients that prostate cancer is like having arthritis or cardiovascular disease; it's a long-term situation for the majority of men. If you have arthritis or heart disease, you treat it with medications and develop different treatment programs. I admit, it's hard to do that for yourself.

DR SCHELLHAMMER: I think the point that urgency is not a critical issue in prostate cancer treatment needs to be emphasized to patients, and they need to obtain other opinions. The most unhappy patients are those who propel themselves into a treatment straightaway, because they think that it has to be started sooner rather than later.

Heart disease is often more lethal than a diagnosis of prostate cancer; however, after a cardiac event, the idea is that you are going to partner with your organ to have a better lifestyle — exercise, and together go forward as a unified team. With cancer, there is a sense of betrayal, and treatment is an effort to rid yourself of the invader.

Having experienced both, I would say that the gut reaction with cancer, although I certainly know better factually, was much more powerful than the aftermath of the myocardial infarction.

Maybe it's one event that happens and then you begin to recover; whereas, the cancer is a process and a journey that you have to move into. Cancer is the big "C," and that term or label still carries

a lot of power. I don't know whether it's an American cultural bias — it would be interesting to hear a similar discussion in France or Norway.

DR LONG: I'm in private practice in an area that is socioeconomically unsophisticated, and I see a lot of prostate cancer. It's almost epidemic in the area. Whenever I perform a prostate biopsy, I schedule a consultation with the patient three to five days later to talk to him face-to-face about the result, whether it's positive or negative.

Patients have plenty of time with me and I think it's very helpful. The other thing I notice is that for some reason, women seem to handle these situations better than men. I strongly encourage patients to bring their wives or daughters.

DR LANGE: I thought about the watch and wait concept — should I do nothing — because I had one millimeter, Gleason 5 prostate cancer. I considered different ideas but I wanted to know what was in there. I felt young then, but since this experience I have become more sensitive to brushing off the 70- or 75-year-old patient by saying, "Oh, well, you're too old."

Echoing Paul's comment, you don't form a loving relationship with your prostate cancer as you might with your heart or your aortic aneurysm, so it's difficult to know what to do. If I see a man who's older, I first find out about his past history and encounters with his own mortality.

If he's had a big MI or whatever, watch and wait could be much more of a reasonable option. If he has never been sick a day in his life and you tell him he's supposed to watch his prostate

cancer, that isn't going to play in Peoria. You have to individualize the treatment for the patient.

Ultimately, I think the answer to Judd's question is a difficult one because once you know that you have cancer it becomes very hard to contend with, no matter what your age.

DR LOVE: I'd like to explore this more. I'll make the argument that you're going to influence the mortality of a man with Gleason 6 prostate cancer, who is 40 pounds overweight, more by doing stomach stapling than by doing a prostatectomy.

DR MAGRINAT: In my practice, for a woman with a three-centimeter breast tumor and one positive lymph node, the discussion takes 35 minutes, whereas with DCIS, it can take up to an hour and a half to convince a woman that maybe it's just a pre-cancer. In fact, I used to say, "This is not a cancer." Then that got very confusing. The patients would say, "Well, do I or don't I have cancer?"

I don't do that anymore. Now, I say, "You have cancer, but it is very early. It's not life threatening, to the best of our ability to tell, and you are going to do fine, no matter what." That discussion takes an hour and a half, whereas deciding how to treat a much more dangerous tumor takes very little time.

DR SHIMM: Sometimes prostate cancer therapy seems to follow the old saying, "When the only tool in your box is a hammer, all your problems start to look like nails." The urologists recommend surgery, and the radiation oncologists recommend radiation. The initial multidisciplinary team should include a medical oncology consultation.

The medical oncologist can act as an honest broker who really doesn't have a vested interest in treatment one way or another, and can advise patients without pushing them. One of the problems is reimbursement. The time you have to spend with a patient is not reimbursed.

DR LOVE: I think the issue of where the medical oncologist fits in prostate cancer management is very important, particularly for patients with biochemical relapse. It's the only situation I can think of in cancer medicine in which oncologists get involved with systemic antitumor therapy at such a late point in time.

RICHARD: One more comment about watch and wait: It's really a burdensome strategy for the patient.

When you look at the nuts and bolts — the periodic biopsies, frequent PSAs and mulling over what they mean and what your wife is experiencing as you harbor the enemy within the gates — it is difficult. I heard from a radiation oncology colleague that very few of the large group of patients that he watches end up continuing to watch and wait. And it is usually the wife who "pulls the plug" on it, because the anxiety is simply too much to bear. It's one thing to think about it, but it's another thing to harbor it yourself.

DR LAWTON: It makes me sad to think that if we have a hammer as a physician, then we think of everything as a nail. I try to tell patients when I see them, "If your surgeon says the only option is surgery and you have low-risk prostate cancer, you need another surgeon. If the radiation oncologist says the only option is seeds, you need another radiation oncologist."

The bottom line is that patients ought to be seeing at least two consultants. If anyone says you need treatment right away, you also need another physician, because the business of prostate cancer is huge in our country.

Sadly, we haven't done enough to say, "Stop it. Don't scare the life out of these patients." Instead we should be telling patients who want surgery or seeds tomorrow, to take a deep breath and ask, "Did you consider all the options?" Then, we should suggest a minimum of two consultants: a urologist, a radiation oncologist and maybe a medical oncologist to consider watchful waiting or hormones alone, which would be appropriate for some patients.

Finally, after they've got that information, they should allow themselves and their spouses or significant others a minimum of two weeks to consider these options before actually acting on it.

DR LANGE: While we're admonishing ourselves, I think we should all remember that we have done a very poor job developing the culture and discipline to do the randomized trials that need to be done. As you know, we failed at SPIRIT.

DR LOVE: Could you review the SPIRIT experience for us?

DR LANGE: SPIRIT was a randomized trial for patients with low-risk prostate cancer comparing seeds and radical prostatectomy. The study was abandoned because of poor accrual. The reasons it wasn't initially successful are multiple and mostly not very not complimentary to the field; however, one of the things that should come out of this meeting is a resolve

that we need to do a better job at clinical trial participation, as in many of the other types of cancer, and not be so entrepreneurial about all this.

DR STUTZMAN: When I was at Hopkins, I saw patients come in from coast to coast, and some of them already had a half a dozen expert opinions. I used to tell them, "You can see six experts and get half a dozen expert opinions. They all may be right, but you have to decide." I told them my experience and what I would have done in their case, but some of these patients were still confused after talking to all those experts. How do you get them to decide what to do?

DR LONG: When I talk to patients with an initial diagnosis, I give them all the options. Then I give them my recommendation because they can get very confused and most of the time there's a little bit of a negotiation.

Some patients don't have transportation to drive 30 miles for radiotherapy. These kinds of things you can negotiate. I think it's important to give them all the options and then give your best recommendation for that patient.

DR MOUL: Urology is a mixture of surgical and medical therapy. I think we're very proud of the care we give to prostate cancer patients, but problems exist. In the past, financial pressures kept us from referring patients, but that's changing as a result of multidisciplinary programs.

We had a good program at Walter Reed when I was there. The problem, in the real world, is that my colleagues complain that if they spend their time in a multidisciplinary clinic; they can't generate the revenue they could in a

regular clinic. That's a fact of modern practice, even though the vast majority of urologists believe, philosophically, that the multidisciplinary clinics are the right thing for patients with early-stage prostate cancer.

Some urologists have voiced concern that they want to send patients to radiation oncologists, but that radiation oncologists always give radiation, bash surgery and don't talk about watchful waiting. I know that's not true in all cases, but it needs to be addressed.

DR SCHELLHAMMER: It doesn't matter who gives the therapy, as long as the patient receives it appropriately. I think it's going to be interesting in the next several years as a number of noncytotoxic biologic agents come to the forefront that do not cause leukopenia and hematologic difficulties. Who will be prescribing them — urologists or medical oncologists?

Treatment side effects and complications

DR MAGRINAT: I love my urologist — I think he is fantastic; however, maybe he thought that I already knew all I needed to know. He made a couple of comments, but it took me a while to figure out that if I had no seminal vesicles, nothing was going to come out — I was going to have one of these blanks.

The next thing that happens is that you have these little periurethral glands, which do produce some semen. I didn't understand what was going to happen to me. I think patients have a lot of very specific questions they want answered. For example, they need to know that they can have an orgasm, even if they don't ejaculate, and that it's going to be dry, but it may not be dry all the time.

DR ROBERTS: One of the areas that needs to be discussed more thoroughly — I can say this from my own personal experience — is the difference between erectile dysfunction and being castrate.

Tremendous emphasis is placed on the importance of erectile dysfunction,

and I think that's an extremely small part of the side effects of hormonal therapy. We need to discuss what it's like to be castrate, so our patients have a better understanding of what their life is going to be like.

DR LOVE: What about the dynamics between the patient and spouse: intimacy, touching? Are these the kind of things that we should be discussing with patients? What happens to couples during this period of time?

DR SHUMAN: Although it may not be practical, I think these issues should be discussed with the patient and their significant other before treatment. It becomes more difficult to discuss after treatment when patients are recovering from the surgery or radiation.

Another issue is libido. For men who are chemically castrate for the long-term (more than three months), that's a huge issue. It becomes even more complicated when you are talking about men in their fifties.

We need to articulate these problems and study how best to address them. I suspect that for most men around the

table here, who have been treated — and I was treated 11 years ago — those kinds of discussions were secondary and tertiary in their encounters with their physicians.

RICHARD: Getting back to the twin fears of incontinence and sexual dysfunction, especially for younger patients — in my own case, just shy of 60 — I think some men are avoiding care. Once you have gone through this, you discover who else has the problem. They talk to you, or you hear about them. I know of at least two colleagues with gradually rising PSAs who are avoiding care because they're afraid of losing sexual function and becoming incontinent.

Many of us have to face the fact that we haven't been well educated. We're not knowledgeable in the way we need to be. We didn't get good sex education in medical school. That probably has been corrected to some extent in the 1980s and 1990s.

You discover the difference between Cialis® (tadalafil), Levitra® (vardenafil hydrochloride) and Viagra® (sildenafil citrate). If patients who haven't been diagnosed were educated about the disease, we'd see a lot of people coming out of the woodwork for treatment.

DR LANGE: This is a changing scene. Urologists are seeing more and more patients on Viagra, etcetera, not because they have to have it, but because it makes it better. Is that a patient who should undergo sexual nerve-sparing or not? It's causing havoc with our databases, in terms of trying to figure out what to tell the patient about what to expect.

The other observation I'd like to make is what I call renegotiating the contract. How many of us have seen couples where the man is on Viagra, and the woman says, "Whatever." These couples first struggle with whether they're going to regain their potency, then with all the three Viagra-like drugs, then injections, vacuum devices and maybe penile prostheses.

Very often they just say, "Well, heck. We have the grandchildren. What are we doing?" It's often initiated by the wife, but female sexual dysfunction is another whole category. Preoperative education and postoperative early intervention, before they get exhausted, have not been emphasized enough.

DR DEETHS: Another important issue is incontinence. We've made a significant effort to train our nurses to talk to spouses and patients about the various diapers and products that are available on the market, which most men — myself included up to that time — have no idea about.

You've got people who come into the office and promote stuff, but many items are available on the market and patients need to be educated about them. Since I experienced the problem firsthand, we've trained our office staff to help patients understand what's available and where to get it.

DR MOUL: I think clinicians probably need to do a better job with education. A lot of resources are available, such as the National Association for Continence (www.nafc.org, 1-800-Bladder). They have an excellent resource guide that lists all the different products that are available.

Case discussion: Maximal androgen blockade and radiation therapy for PSA relapse

DR SCHELLHAMMER: My Gleason sum was high and I had biochemical failure within a year. After a lot of discussions with urologists, it seemed that distant failure had occurred, because of the high score, the rapidity of the rise and the fact that my pathology with regard to local extension was excellent. My tumor had negative margins and I had negative seminal vesicles, so the likely presumption was that the disease had a systemic component.

At that time, Dr Taplin was just coming out with some of her early information about the combination of chemotherapy, the taxanes, and androgen deprivation, and I thought it was perhaps a good schema to think about. Even though the toxicity profile of taxanes is acceptable, it's still considerable, so I decided to proceed with radiation therapy and androgen deprivation, without chemotherapy.

If I had a systemic component and my scans were all okay, then perhaps hormonal therapy would be effective in synergizing with the local therapy for local disease, as well as perhaps systemic disease. I took complete androgen blockade for six months using both an LHRH agonist and 50 milligrams of Casodex® (bicalutamide) as an antiandrogen, and I did not have particular difficulty with hot flashes. These were present, but certainly not debilitating.

I didn't have to change my shirt or night garments, but I did have rather significant fatigue and I thought my ability to add and subtract (or at least to multiply) was somewhat less, so my

cognition was decreased. It became clear that I was a laboratory for how we are driven by our hormonal environment, because my libido and sexual interest just evaporated to the point that even the prettiest damsel didn't even negotiate a look.

Fortunately, after the six-month regimen, my testosterone level eventually rose and I've recovered, but it's impressive how you are a product of your hormonal environment when it is suddenly altered.

DR FAGAN: This is very interesting because I had a Gleason 9 and no local extension, yet my PSA was present and doubling in a very short period of time. I had not had a preoperative CT scan so Mary-ellen Taplin insisted that I have one, which I did. Everything else was negative, but I had two nodes — one large obturator node on each side, which is probably where my PSA was coming from.

I chose docetaxel and exemestane and hormonal ablation. My testosterone now is about 90, but at one point it went down to 30. Normal is in the 600 to 800 range, so I'm still in that phase.

I had terrible, horrible, awful hot flashes and they occurred frequently. It's interesting when you talk about mentation. My wife noticed some changes. I'm 81, so I thought maybe it was my age that was causing it, and that may be part of it, but I'm sure the treatment contributed to it.

DR LONG: I'm just a country urologist but we used to treat people with DES (diethylstilbestrol), which would

not result in hot flashes. Then we'd treat them with Lupron® (leuprolide acetate) and so forth. I know most people do not give any sort of female hormones to these patients.

I take Zoladex® (goserelin acetate) myself, and I take estradiol daily because after about three months on Zoladex, working full time all through this period, one afternoon I just felt like a wilted plant. I started taking estradiol and all these things disappeared.

Physical contact became an important part of my relationship again, and I do appreciate pretty girls walking down the street, so I'm curious why more people do not receive some sort of female hormone replacement when they're on Lupron and so forth.

DR SHUMAN: Tom Beer at the University of Oregon has begun to do some research on transdermal estrogen patches, which have been studied more intensively in Europe.

One of the reasons for embracing this as a potential alternative to the LHRH agonist is that preliminary evidence indicates less of a deleterious effect on mentation with the estrogens, possibly even a beneficial effect in terms of osteoporosis, and because it's transdermal, the risk for thromboembolic disease does not appear to be increased.

Another potential benefit of transdermal estrogen is that it would be infinitely cheaper than an LHRH injection, but the patches are not currently available in this country. The available patches are too low a dose so patients must use multiple patches, which is impractical.

So far no pharmaceutical companies have been interested in pursuing this, but hopefully the prostate SPORE mechanism that Paul and I belong to will study this as an alternative to the LHRH approach.

Why differences exist between using estrogens versus LHRH is not clear, but it is clear that abundant androgen receptors are present in the brain and the estrogens cross the blood-brain barrier. Considerable research is needed to develop treatments for men who are forced to be on some kind of hormonal therapy.

DR LANGE: As with testosterone, the estrogen patches are not terribly convenient. The gel form of testosterone has changed everything, and I think the same thing will happen with estrogens, not to mention cognition and osteoporosis. The only downside is gynecomastia, but we have some interesting ways around that, besides pretreatment radiation.

DR LOVE: What about the issue of antiandrogen monotherapy with 150 milligrams of bicalutamide? This has been a fascinating story evolving over the last couple of years. At the AUA meeting, we had a think tank of clinical research leaders, and antiandrogen monotherapy was one of the topics. Patients are aware of the controversy about selection of primary local therapy, but I'm not sure they're as aware of some of the controversies about timing and selection of hormonal therapy.

During the think tank Bill See discussed the issue of 150 milligrams of bicalutamide in the EPC trials and the various side-effect profiles. Laurence Klotz did a presentation on

maximum androgen blockade, which was very interesting.

Judd, you did a presentation there about timing of intervention in terms of PSA relapse. Would you review the issues about timing and selection of therapy, and how can we involve patients more in making the best decision for themselves?

DR MOUL: It's a very controversial area and, like so many other areas of prostate cancer, we do not have a lot of randomized trial data to go on, which makes it difficult to practice evidence-based medicine. Randomized trials suggest a benefit from traditional early hormonal therapy in men who have lymph node metastasis after radical prostatectomy or men with traditional metastatic prostate cancer.

We have absolutely no randomized trial data in patients with biochemical recurrence, and they are the most common patients who are going on hormonal therapy.

We published a paper based on data from the military database evaluating a whole bunch of guys who had biochemical recurrence. We compared the ones who received early hormonal therapy to the ones who received late hormonal therapy. Again, it was not randomized.

We found evidence suggesting that early hormonal therapy seems to benefit the guys who have high-risk biochemical recurrence, delaying the development of bone metastasis; however, our follow-up was too short to show survival benefit.

In the overall group of patients with PSA recurrence, we were not able to demonstrate any benefit. The doctors out there who are anti-early hormonal

therapy can look at our data and say, "Ha! Told you so. There's no benefit to early hormonal therapy." On the other hand, for patients with high-risk disease, early hormonal therapy offers some benefit.

DR LOVE: Paul, you chose to be treated with MAB even though a minority of men in your situation are being treated that way. I was impressed by Laurence Klotz's presentation in which a comparative analysis — including a lot of your data — suggests that using MAB with bicalutamide may offer a 20 percent improvement in mortality compared to an LHRH agonist alone. What are your thoughts on that and why do you think more men aren't receiving that type of therapy?

DR SCHELLHAMMER: I think the reason more men are not receiving it is financial, budgetary and economic. If antiandrogens cost a nickel or a dime or a quarter a pill, my personal conviction is that everyone on androgen deprivation would be taking CAB. The large meta-analysis experience of the randomized trials shows an overall survival benefit that may be small, but is statistically significant, and it's in a group of elderly men for whom an overall survival difference is quite impressive because of the other competing causes of death.

No trials have compared combined androgen blockade with Casodex to LHRH monotherapy. With some statistical manipulations, which some individuals find distasteful but has precedence in FDA-reviewed trials, as much as a 20 percent reduction in death occurs with that combination versus monotherapy.

I believe we should take every little incremental benefit we can and apply

it as a standard. In answer to your question, the economics certainly become a big obstacle because of the cost of the drug and the fact that it's not covered by many insurance carriers.

DR LOVE: Colleen, to me, this is a unique situation in cancer. Dr Klotz drew cost-benefit analogies to other types of interventions in cancer and showed data suggesting that MAB is comparable, maybe even better in terms of calculations of dollar per life saved, etcetera. What are your thoughts on that?

DR LAWTON: I couldn't agree more with Paul's comments about finances. This isn't a small financial impact. It's a huge financial impact. Many of these elderly individuals are on fixed incomes and they just don't have the resources to consider that.

Paul is right, the data support combined therapy if you look at the meta-analyses, yet the differences aren't huge. Very often, the wives are making these choices, or I watch the wife say to the husband, "Yeah, you know, that's really going to impact us." And they have the option of going on an LHRH agonist, which is Medicare-covered, or paying out this big dollar amount for MAB and they choose the LHRH agonist and say, "Well, the benefit isn't really that much, so I'll probably be fine with that."

DR LOVE: This may be a men versus women, breast cancer versus prostate advocacy issue. I believe that if something like this were going on in breast cancer, it would be on the front page of the *New York Times* every day. Yet I don't hear people talking about it.

Do you think the option of MAB should be presented to men who are going to be receiving hormonal therapy, or are physicians not bringing it up because of economic issues?

DR MOUL: I agree 100 percent with Paul and Colleen. I experienced it firsthand in just the last six weeks. My previous practice was in a socialized setting where the antiandrogens were covered, and we basically gave the patients the benefit of the doubt. Virtually all patients went on combined androgen blockade because of the modest but real survival difference.

The corporate culture, if you will, in my new practice setting is that the doctors basically just make the assumption that the patients don't want it and don't want to pay for it. When they put a patient on hormone therapy, they just write a prescription for 10 or 12 days of oral antiandrogens to block the flare, and don't even bring up the option. They just assume the patient is not going to want to bear that cost.

DR LOVE: Shouldn't that be the patient's decision? I see you shaking your head, Gus.

DR MAGRINAT: This is like aromatase inhibitors costing \$400 or \$500 a month in breast cancer. I always tell my patients, "Look. This is a marginal improvement, but it is an improvement; fewer side effects, a little bit more benefit, but much more costly. If you can't get it, we'll try to get it for you," because the companies do have programs to provide the drug to indigent patients.

I discuss it with them, and they make the decision. "No, I really can't afford it. I don't want to try." In those cases, we may use tamoxifen, which is not

bad at all. But the cost of Casodex may be overwhelming.

DR MOUL: Monotherapy with bicalutamide is even worse. In my previous job I used a lot of Casodex 150. I was kind of patted on the back, because in the socialized system, when I tripled the dose of Casodex 50 and gave that to a patient and avoided an LHRH agonist, believe it or not it actually saved our healthcare system money. We have no incentive to do that outside that socialized setting. In fact, I have not yet prescribed Casodex 150 in my new practice.

DR LAWTON: Just so that we don't think that Casodex 150 has no complications, about 75 percent of patients on Casodex 150 get gynecomastia. We ran an RTOG trial in which patients with a postoperative rising PSA underwent postoperative radiation with or without Casodex. It was a placebo-controlled trial but, clearly, you could tell the patients on Casodex because the gynecomastia was very obvious. My point is that Casodex is not without side effects.

The other side of the LHRH story as far as side effects are concerned, having had my dad on it both long-term and now intermittently, is that some people really tolerate it exceedingly well. He virtually has no hot flashes. And my dad, God bless him, he'd complain about it, if he had hot flashes.

And my mother, as far as their intimate relationship is concerned — they don't get specific about sex but my mom would say that my dad's actually more affectionate now, more sensitive, than he ever was before.

DR LOVE: The theme that has been adopted in a lot of other cancers —

and, again, I keep coming back to breast cancer — is trying to involve the patient in these kinds of decisions. With regard to a lot of the things that we've talked about today, I don't see patients with prostate cancer as involved in their own treatment.

It bothers me, looking at it from the outside. People can make whatever decisions they want, but to have the decisions made for them — I'm not sure that's the way it ought to be.

DR SHIMM: Some of it may be an age issue in the sense that breast cancer patients tend to be a little bit younger, probably a little bit less deferential to physician authority. Breast cancer and prostate cancer afflict patients in a wide range of ages but, in general, prostate patients are older and maybe a little more inclined to just nod their head and go along and not ask questions.

DR SCHELLHAMMER: It's also rather difficult when you advise the patient that taking a pill in addition to their shot can add a perceptible and measurable benefit. You become a semantic, word-crafting wizard trying to avoid a situation whereby they feel they are jeopardizing their survival because of money. You don't want them to have that angst, but they need to be aware that this therapy exists.

And then you ask, "Does your insurance plan cover?" And they say, "No." And then you are faced with saying, "Well, it's going to cost you too much." And they'll say, "Well, 'too much' for life is not within my vocabulary or thought process." And then you mention the cost and they say, "Well, we might not be able to pay the rent."

It's a time-consuming and discouraging conversation. I often have my

nurse go in first and find out what their insurance situation is right from the get-go. Then I make a bit of an arbitrary decision that, if they don't have any coverage, I'm not going to go into detail about this added expense, other than to maybe mention it peripherally.

DR LOVE: Colleen, you were talking about gynecomastia. Could you comment on what methods can be used to decrease the chance of that happening?

DR LAWTON: We can give low-dose radiation therapy preemptively to prevent gynecomastia from occurring. Once the gynecomastia has occurred, we can prevent it from getting worse.

Often, we can eliminate the pain issues but we can't reverse the gynecomastia, so if a patient is going to take Casodex 150, my bias is we ought to do it sooner, rather than later.

DR LOVE: Paul, does gynecomastia occur with CAB?

DR SCHELLHAMMER: It's a rare event and I did not have that problem.

DR MAGRINAT: Going back to your comment on information release, in medical oncology, we frequently have treatments that patients cannot afford and we always tell them about it. It's just a different way of doing things. Whether it's better or worse, I don't know.

I have a patient with true Philadelphia chromosome-negative CML and no one will pay for his Gleevec® (imatinib mesylate). But he responds to Gleevec so he actually spent \$1,800 of his own money to buy a couple of months of Gleevec, and it worked.

Whether he can keep it up or not is going to be his and his family's decision. I can't obtain it for him. No one will pay for it.

That happens all the time with bone marrow transplantation. A transplant might really make a difference to a patient, but they don't have insurance to cover it. It's a terrible situation, but you didn't create it and it's not your ultimate responsibility.

I am more concerned about taking responsibility for providing information to a patient who comes to me for information. I lay it all out on the table. It is unfortunate and hard to deal with, and it may be unjust, but I don't take that responsibility.

DR MOUL: I was really struck by what Paul said, and I didn't know his full story until today, with regard to his radiation.

It struck me that in settings such as his, with a Gleason 8 and a patient who has a relatively rapid recurrence, I have been very pessimistic about radiotherapy. Perhaps I'm doing patients a disservice.

On one hand, we don't have any randomized trial data to suggest that it's beneficial in that setting. On the other hand, I recommend hormonal therapy without any problem in that situation without randomized trial data.

I have bashed postoperative radiotherapy in similar settings, but I'm going to try to be a little more empathetic with my patients in the future.

I honestly can't say what I would do if I were diagnosed with prostate cancer, although I was also struck to hear that

the “C” word has such an emotional impact — even among physicians who know a lot about prostate cancer and

know that it’s a whole spectrum of disease.

Psychosocial issues in prostate cancer

DR LOVE: What is it about the word “cancer” and the disease itself that is so unsettling? In many situations cardiovascular disease can be much more life-threatening. What is it about our culture and this disease?

DR LAWTON: I think one of the things that stirs that visceral reaction, especially in physicians, is that we can’t help but think of that patient who did extremely poorly.

When my dad was diagnosed, his PSA was 93, which was overwhelming. He didn’t get screening PSAs because he believed that screening is a way for doctors to make money, which is neither here nor there, but that is what he thought.

With a PSA of 93, I immediately assumed he had bone mets and a whole litany of things, as did my brother who is a physician. When all of his scans came back negative, it was surprising. In fact, my dad looked at me and said, “You’re surprised.” I said, “I am.”

DR MOUL: Neil, I thought the audio program Colleen did with you about her father was very moving. We’ve been talking about conveying optimism and I want to comment about my father-in-law.

He was diagnosed with prostate cancer in the late eighties right at the beginning of the PSA era. His PSA was approximately 40 and he had what was interpreted as a negative bone scan and a negative CT.

Like any good son-in-law surgeon, I encouraged him to have a radical prostatectomy and referred him to one of my buddies from medical school who did a radical prostatectomy and, not surprisingly, he had non-organ-confined disease.

I then referred him to one of my other buddies, a radiation oncologist, and he underwent postoperative radiation therapy. Then he had a PSA recurrence. I kept reassuring my family that prostate cancer is not a lethal disease, and that we were going to have him a long time.

He was dead within 36 months of the diagnosis, and I feel like I let my family down because I kept reassuring them that he was going to be with us. He had the one “way out on the bell-shaped curve” case of prostate cancer that we occasionally see in practice.

DR DEETHS: To go back to your original question about why cancer has such a bad connotation: Cases like this are the reason. Many of us grew up in a time when surgeons would say, “Well, I opened and closed the patient and there was nothing we could do.” At that time, cancer was a death sentence and that’s what most of us remember.

RICHARD: If we go back a couple of generations and talk to our parents or our grandparents, they recall a time when cancer was actually a shameful diagnosis — something to be concealed.

Even now, if you talk to patients with European backgrounds and some other cultural backgrounds, it's still

so terrible that you can't even name the word.

Case discussion: PSA progression after intolerable side effects from chemical castration

DR ROBERTS: I was diagnosed with prostate cancer in 1999, and my Gleason score was nine (4+5) and my PSA had doubled in the year before.

It was considered to be locally advanced and surgery was not recommended. I was initially treated with intensity-modulated radiotherapy (IMRT) at about 71 Gray.

I also received maximum androgen blockade before and after the IMRT, so it was about six months of treatment and then I didn't receive any kind of treatment for about 18 months before I had a PSA relapse.

At that point I went on leuprolide, and that was the worst experience of my life because of the weakness and the chemical castration.

I remember meeting with my radiation therapist when I was undergoing treatment. I was chemically castrated at that point. He said, "How are you?" I said, "Fine, for a eunuch," because that's exactly what I felt like.

DR LOVE: Can you talk a little bit more about what was going on and why you felt so bad?

DR ROBERTS: The hot flashes were intolerable. I had to stop wearing ordinary shirts and sweaters and start wearing cardigan sweaters so I could get out of them faster without breaking out in a sweat. I was examining a patient, and I would suddenly start to sweat; the same thing happened in bed at night.

Weight gain and redistribution was also a big issue. I was a competitive tennis player and I couldn't beat anybody anymore, which was not easy to take.

I don't know whether this is related or not, but I developed a supraventricular tachyarrhythmia. I haven't heard anybody else mention that, but I had one spell of SVT, and constant PACs that were rather annoying. I had no history of heart trouble — it could have been a coincidence but it occurred while I was on Lupron.

Last year I listened to the *Prostate Cancer Update* series and learned about Laurence Klotz's work with intermittent therapy. I have two friends who are urologists at Brown University, who thought it might not be a bad idea to go on intermittent endocrine therapy since I was having such a tough time with the antiandrogen. So I stopped everything.

I had my last injection in May of 2003 and since then I've had a PSA and a testosterone level every two months. After about five months I began to feel like a human being again. I still had erectile dysfunction, but I wasn't a eunuch.

I had a very passionate relationship with my wife prior to all this, and then she became a good friend, sort of a buddy. I couldn't stand that feeling. After I got off of the leuprolide, we became lovers again. I did not have

good erectile function, but that is a small part of the whole thing.

Since then, I've been watching my PSA, and in the last month it has tripled. It was 1.6 two months ago and it went up to 4.2. Next month or the month after I'll be getting my next PSA and I have to decide what to do at that point. I won't go back on leuprolide. I'd rather die. Bicalutamide monotherapy has been suggested, and I'd be happy to hear any comments or suggestions from any members here.

DR LOVE: What's your wife's perspective on this right now?

DR ROBERTS: She wants me around as long as I can be here.

DR LANGE: Alan, as a medical person, do you have any theories on why your reaction to androgen deprivation was so extreme compared to some other men who say, "Ah, it's nothing."

DR ROBERTS: Sure, because I was so much more macho! (Laughter from the group.) No. I have no idea.

DR LOVE: Do you have any theories, Paul?

DR LANGE: No, but I'd just like to get every one of these people an FMRI or something, to figure it out.

DR LOVE: Do you think this is unusual? Is it uncommon to see men who are totally miserable on androgen deprivation?

DR LANGE: I see it a lot, but I see more who say, "Ah, no big deal." And I've never been able to postulate why that is, other than the fact that it's endocrinology and something to do with neuroendocrinology.

DR LOVE: Judd, how would you think through this situation?

DR MOUL: It might have something to do with androgen levels when the person starts the therapy, but that's too simple, and I'm sure it has been studied to see if the initial testosterone level has anything to do with the complex androgen receptor pathway.

We're learning more about the antiandrogens — different ones behave differently. A lot of other things impact the androgen receptor — other molecules — and that's just starting to be elucidated.

We don't know anything about hot flashes or why they occur. It's another example in which we don't really understand the physiology.

DR ROBERTS: I took progesterone when I was desperate and it worked. It stopped the hot flashes so I could manage.

DR LOVE: What about bicalutamide 150 in this situation?

DR MOUL: Most of the patients, the younger ones who had libido and sexual function at the beginning of therapy, seemed to be able to maintain that, or at least to continue to respond to Viagra or one of the other agents. I have never seen a patient who had hot flashes on bicalutamide 150.

The question is: If a guy is on that therapy for a long period of time, will he gradually lose his ability to respond sexually?

Or will he gradually lose libido over time? I don't know if that has been studied, but in the short term, the younger guys seem to be able to maintain their function in that regard.

DR LOVE: Alan, you talked about trying intermittent therapy, but that's

still going to involve going back on androgen deprivation.

DR ROBERTS: Based on what I hear, I probably would be willing to try high-dose bicalutamide.

DR SCHELLHAMMER: Another alternative is multiple transdermal estrogen patches, and follow your testosterone to see how many you need to put on each week. It's relatively inexpensive. The cardiovascular side effects are abrogated by bypassing the liver, so that certainly would be less expensive and you wouldn't have some of these other side effects, except the gynecomastia, which you can preempt with radiation.

DR LOVE: Have you actually utilized that in your practice, Paul?

DR SCHELLHAMMER: I have not as primary therapy, but as secondary hormonal therapy in individuals already on an LHRH agonist, so you don't have to put on as many patches. They already have a castrate T level.

I can't tell you a percentage but I'll say a third, in a small experience, have a dramatic PSA response. We knew estrogens had effects on prostate cancer cells other than the endocrine axis, and I think that it's a reasonable thing to try in elderly individuals for whom you want to avoid more toxic therapies.

DR ROBERTS: But patients will still be castrate?

DR SCHELLHAMMER: Yes.

DR LANGE: One has to remember that the patches are estradiol, not DES. DES still hasn't been put into any kind of a formulary.

I happened to be involved in discussions that involve the FDA, about getting estrogen re-approved for delivery in a manner other than through the compound pharmacies. They are not making it easy.

DR ROBERTS: What about the idea of continuing some type of intermittent therapy, such as high-dose bicalutamide or estrogen patches for eight months or so?

DR SCHELLHAMMER: It would be an entirely new arena because intermittent Casodex has never been studied.

DR ROBERTS: If the PSA is any indication, you would at least have that to follow.

DR SCHELLHAMMER: Correct. That's what you're treating. But your PSA doubling time is worrisome, so treatment is something you need to strongly consider, however you decide to embark.

DR SHUMAN: I don't know if it's been published yet, but preliminary evidence indicates high-dose Casodex resulted in an increased incidence of death. It's not clear what those deaths were due to, but I would be more cautious about going that route.

DR LOVE: Judd, you were one of the reviewers for that paper, correct?

DR MOUL: Yes. I don't know if it's out yet, but it will be published in the *Journal of Urology*. It's by Peter Iverson. As a reviewer of the paper, I couldn't make heads or tails of it.

The bottom line is that the patients with localized prostate cancer who went on Casodex in the Scandinavian watchful waiting part of that international trial had a higher overall death rate than patients with localized prostate cancer

who were on placebo. No clear reason exists to explain why.

No one type of death predominates — a multitude of deaths occurred — yet it is statistically significant. At this point, the clinical relevance of this is uncertain because it's just a matter of a few deaths making the one arm statistically significant.

I think they're reporting it to alert people. I studied that paper carefully but it was not a show-stopper for me. I would still use Casodex in a patient at high risk who really needed it.

I would, however, be reluctant to use it in a patient who didn't really need it, such as a patient at low risk for whom watchful waiting would be appropriate.

DR ROBERTS: The difference between absolute risk and relative risk reported

in the literature is large, and we have to be very careful when we review studies, as to what we're considering.

For example, if you consider the risk of breast cancer in women who are taking estrogen, the relative risk is about 28 or 29 percent.

But if you consider the number of patients per 10,000 per year on estrogen who develop breast cancer, it's extremely small. In this particular case, I don't know whether the difference between relative and absolute risk is significant.

DR ROBERTS: The one thing I am curious about is why I developed an atrial arrhythmia. It hasn't been reported and I haven't heard of anybody else having that happen. It could have been just total coincidence.

Case discussion: Androgen deprivation for metastatic disease

DR SHIMM: After my dad's prostatectomy, he had positive margins and his PSA never went down. He was on Lupron until he started chemo.

Although he has bone mets, he has been asymptomatic from them. The toxicity he has experienced — lassitude and intellectual dullness — is not from the disease, but from the treatment.

He's a retired law professor and just can't quite get things straight anymore. His weight is about the same, but his waist is about four inches bigger, so he's gaining fat and losing lean body mass. The hot flashes are also an issue, although these have stopped now

that he's off Lupron. A lot of patients complain about the hot flashes.

I assume we have the bone density loss pretty much under control, at least theoretically, with the bisphosphonates — provided patients receive them. I'm more concerned about how to deal with the day-in and day-out grinding-down effect of some of these drugs on a patient's quality of life.

DR LOVE: How old is your dad? How long has he been on therapy, and how has his lifestyle changed while he's been on therapy?

DR SHIMM: He's 78 now, but he was a healthy 72-year-old when he had his prostatectomy. He had recently retired and was very active, running daily

and traveling a lot to visit my wife and me and the grandkids.

At this point I wouldn't call him housebound because he goes out and still drives, but a long trip is out of the question for him. He takes a lot of naps and has certainly given up all kinds of exercise.

DR LOVE: And how was the metastatic disease picked up? Symptomatically or just in scans?

DR SHIMM: Just by scans.

DR LOVE: So, he has asymptomatic metastatic disease?

DR SHIMM: That's right.

DR LOVE: And his life is not very pleasant right now because of the treatment?

DR SHIMM: Exactly. The impairment of his life is solely because of the treatment, which is not to say the treatment hasn't done him some good, but he's experienced a fair bit of toxicity.

DR DEETHS: My personal experience was that I went through a period of depression, and you wonder whether men with metastatic disease might have an element of depression that is really not recognized, and whether that can be part of the disease process and the treatment process that we, as physicians, overlook.

DR LOVE: Can you talk a little bit more about what was going through your mind in that regard?

DR DEETHS: My initial feeling was that I was going to die from cancer, which is a typical reaction. As I mentioned,

for six months I wouldn't buy any new clothes or shoes or socks or anything, because I felt that I had enough in my wardrobe and I was not going to outlive anything that I bought. I realized that I was depressed and I talked to my personal physician, but I didn't believe I needed any medication.

Even now, seven years later, I go through periods during which I feel sort of down. I know it probably stems from my diagnosis more than anything, and every day I'm reminded of it — either by a little bit of incontinence or an urge or the stress of incontinence, or when you go to have sex and have to use some pill or device. I realize other men do that but it causes stress. I use CarboJet™.

DR LOVE: Another thing that becomes an issue for a lot of people is the marital relationship.

DR DEETHS: My wife tends to not be very introspective about things — about her own health and so on, and she did not give me a lot of support initially. I was getting more support from my office personnel.

As far as intimacy, our personal relationship actually improved after about six or eight months. You realize that you're not going to die right away, but you also realize that life does end and you never know how much time is left.

The hugging and the kissing and the touching became very important and that part of our relationship really improved. I think we both feel that way.

Case discussion: Open versus laparoscopic prostatectomy

RICHARD: I watched two good friends go through a conventional radical prostatectomy, and compared to my own experience with a laparoscopic procedure, they are two entirely different experiences.

It's too soon to know whether laparoscopic prostatectomy offers better preservation of sexual function than conventional radical prostatectomy, although some data suggest it might. I'd be interested to hear from some of the urologists how difficult an issue this is and how the Da Vinci robot may help.

DR LOVE: Could you tell us about your experience with that procedure?

RICHARD: It was extraordinary. I was in the operating room at noon on Tuesday, out of the operating room by 2:30 and home Wednesday evening. I felt a little weak, but had no pain and no blood loss.

My recovery was rapid — the catheter was removed after one week and I had my first erection at three weeks. Everything I had dreaded failed to come to pass.

I also have observed what seems to be some professional jealousy regarding this issue in the urologic community.

I had seen friends go through significant blood loss and a lot of postoperative pain and significant debilitation. My experience was completely different. Other patients I've talked to subsequently have had similar experiences, so I don't think I was an outlier.

DR SCHELLHAMMER: I'm out of the surgical business now, but I can say

that at our center, in our department, laparoscopic radical prostatectomy was introduced four years ago and the ratio in that first year was 10 percent laparoscopic, 90 percent open. Now it's just the reverse. In fact, it's 95 percent laparoscopic and five percent open.

We now have three individuals doing laparoscopic surgery. They've all used the Da Vinci machine and say they probably will not go back to the conventional laparoscopic after using the Da Vinci because it's very operator friendly and they avoid all the aches and pains of standing and holding their neck in a fixed position.

DR LOVE: Can you describe the Da Vinci machine?

DR SCHELLHAMMER: It's a robotic machine that has a great deal of visual magnification. It has 3-dimensional perception, as opposed to the 2-dimensional view through the conventional lens.

It has the so-called degrees of freedom, whereby maneuvers can be done by the robot arm in small spaces that your wrist and fingers can't accomplish. The operator sits in a console and operates remotely, away from the operating room table. It's rather futuristic, but it works remarkably well.

DR MOUL: Paul and I were at the Mid-Atlantic AUA meeting earlier this week when the Hopkins group presented their experience with their first 350 laparoscopic prostatectomies, and the results are good — although not as good as the open prostatectomy experience reported by the main

surgeon at Hopkins, with regard to continence and potency rates.

A lot depends on the expertise and experience of the individual surgeon. I think your point is well taken: it's not clear whether the long-term cancer control will be similar. It's likely, but it has not yet been proven.

With regard to the potency rates, I think it depends on how much electrocautery is used. Obviously, you had a great outcome. Whether your case is the exception or the rule, you don't know unless individual surgeons publish their own personal results. That is not commonly done in this country — not just for urology but for any surgical procedure.

RICHARD: An independently refereed study of my surgeon's whole series is underway right now, and they're comparing it internally.

DR MOUL: That's the exact right way to do it. I can tell you that we are now embarking on the robotic at the institution I'm at right now, and the biggest challenge is financial. It is difficult to make ends meet doing that, because the operative times are longer but the reimbursement is the same.

We face a lot of pressures in that regard and, quite frankly, the surgeons' profit-and-loss statements are going in the wrong direction. I don't know what's going to happen. The insurance companies don't seem to want to pay more for it, yet it definitely requires more time to do.

DR LOVE: How available is the procedure? How many centers around the country are actually making it available, and how does it work in terms of paying for it?

DR MOUL: I can't say exactly how many centers are doing it. I know a large number are doing it, and many centers are doing it kind of as a loss leader. They're doing it to try to attract patients to their particular program to generate prostate cancer business.

But right now, most of the insurers are not willing to compensate more for the Da Vinci procedure than for the traditional open prostatectomy procedure. Even in the best of hands, the Da Vinci procedure takes longer to do. That's where the challenge comes in.

DR LANGE: These details are not much different than the details I experienced when urology converted from open stone surgery to percutaneous and shock-wave approaches, with all the great angst about making money, levels of skill, who gets the best results, etcetera.

More centers want to claim themselves as centers for prostate cancer excellence — and it probably will cause more centralization of these skills. The only uncertainty right now is the potential five or 10 or 20 percent differences in potency.

In two years, if surgery is still an option, we'll be doing it laparoscopically and probably with a robot — not because a skilled laparoscopist couldn't do it without a robot, but it turns a good prostatectomy surgeon into a skilled laparoscopist without having to go through all the agony of learning from scratch. Financially, it is a problem, but in medicine anything that costs more is initially rejected, even if it's better. I think it will eventually predominate.

DR LOVE: We talked about patients being made aware of options and

urologists referring patients with low-risk tumors to a radiation oncologist to be evaluated. Do you think urologists should also be saying to patients, “Listen, I don’t do laparoscopic prostatectomy, but I want you to be aware that it can be done and, if you want to find out about it, I can tell you about centers that do this”?

DR LANGE: It would be self-serving to say “yes” but the answer is obvious.

RICHARD: I’m chuckling at that answer because, at least in my local medical community, it was interesting that a couple of behemoth famous institutions were reluctant to give it equal credence or even to accurately present the details.

DR DEETHS: In Omaha, three Da Vinci units are in use. One is in the University of Nebraska; the second one is in a private hospital; and the third one is within 30 miles of Omaha. It’s going to be a ubiquitous procedure and a ubiquitous unit. It costs about a million dollars for one unit but hospitals in Omaha don’t seem to have a problem with that expense.

RICHARD: In oncology, if we have two regimens that are equally effective and one is a lot less toxic than the other, we know which one the best is.

DR LOVE: I’m curious what your thoughts are in terms of the Medicare changes that are coming about and the potential impact on the practice of prostate cancer medicine. Judd, you were commenting earlier about the fact that life is different outside of Walter Reed. What do you think is going to happen over the next year or so in the community?

DR MOUL: I think a lot of us are concerned about the changes in reimbursement and how it’s going to affect the bottom line for both urologists and medical oncologists.

One thing is clear. Some urologists are saying, “We’re just going to write a prescription and send the patient to the pharmacy,” and we can’t do that because these drugs are only reimbursable by Medicare if administered through a physician’s office. We have to find a way to make it work for our patients.

DR LONG: It is a difficult dilemma. I have 60 patients on Zoladex and if Medicare reimburses six percent more than cost, we’re going to lose money because some slippage always occurs. I don’t know what I’m going to do with my patients after the first of the year. I’m looking for help.

Case discussion: In search of a radiation oncologist

DR GALLEHUGH: As a diagnostic radiologist, I’ve had very little experience with cancer therapy, except my own. As you know, the only therapy we do is with a catheter.

I was diagnosed with carcinoma of the prostate, and in choosing my own therapy I took an approach that was

somewhat different than what most people do.

Incidentally, I was called on Christmas Eve by my urologist, and he gave me the diagnosis over the phone. We talked about that earlier today. It didn’t bother me a bit, because I was also being treated for Lyme disease, and the Lyme disease was so devas-

tating that anything else didn't make a difference.

I told the urologist that I wanted interstitial therapy because right after I retired, I joined an NAIC investment club. They meet once a month and somebody presents a stock. One month during the mid-nineties, one of the members presented Theragenics.

I didn't know much about this company, but after he presented it, I went back and studied Theragenics and learned that they make cyclotron-produced isotopes, one of which was palladium 103. They also make iodine 125. I studied those two isotopes carefully and realized that patients treated with either of those two isotopes had significantly improved outcomes.

In the back of my mind I said, "If I ever get prostate cancer and I'm under 70, I'm going to have a radical prostatectomy. If I'm over 70, I'm going to have interstitial therapy with palladium 103.

When I was diagnosed, I was one month from 70, so I said, "That's close enough. I'm not going to have a radical prostatectomy."

I knew the radiation oncologist at the University of Kansas was absolutely set on iodine 125 and he was not going to deviate, so I wasn't even going to talk to him about it.

I called the Theragenics Corporation in Georgia and explained my situation and asked them if they'd be kind enough to send me a list of the radiation oncologists in the United States who bought the most palladium 103. They were kind enough to do that.

This list of radiation oncologists included one in Scottsdale, Arizona,

where we spend the winter. I didn't know anything about this guy, so I called one of my friends who is a family practitioner and asked him to call four of his urology friends and ask, "If you had carcinoma of the prostate and you were going to have interstitial therapy, who would you go to?"

Three days later, he called me back and said, "You know, they all said the same guy. They gave me the same name, all four of them." It was the guy in Scottsdale, so I thought, "Well, he probably is pretty good."

I searched the medical literature and the first paper he wrote reported 500 cases. I looked further and a second paper reported 1,500 cases. I thought, "That's enough. I'll give this guy a try."

I called him up and went to see him and he said, "Your prostate is too big for interstitial therapy." It was 72 millimeters. He put me on hormonal therapy for six months with the intent to do a palladium 103 implant.

I had hot flashes of dynamic proportions, but I didn't want to die so I suffered through the flashes. After six months of hormonal therapy, the gland was down to 40 millimeters.

I had my palladium 103 implant, which was uneventful, and everything since has been uneventful. It was an unusual method of selecting therapy and an oncologist.

DR LOVE: I thought it made a helluva lot of sense. From a patient education perspective, maybe more people ought to be doing that.

What was your life like on hormonal therapy?

DR GALLEHUGH: As I said, I was being treated for Lyme disease at the same time, and Lyme disease is devastating. I had no energy and was completely devastated. Except for the hot flashes, I'm sure it was the Lyme disease, not the prostate cancer, but it was a fairly miserable six months.

DR LOVE: How long ago was that?

DR GALLEHUGH: Two years.

DR LOVE: How are you feeling now?

DR GALLEHUGH: I'm feeling fine. All of the Lyme titers are negative, including spinal fluid.

Watchful waiting for low-risk disease

DR MAGRINAT: Before the lawyers get in there and start suing doctors because they didn't treat someone with a good prognosis, I think we need to develop some guidelines for watchful waiting. For example, if you have a Gleason 4 or 5, do you really need any treatment? Clear guidelines on that would be very helpful at this point. Five years from now, or even three years from now, we might not have the luxury to do that.

DR MOUL: In the CALGB, we've been trying to design a watchful waiting prospective trial. We're having a lot of difficulty agreeing on how to design the study and we're having issues with the National Cancer Institute, because even though it's a treatment, C-TEP is having difficulty deciding whether they're going to fund it because it's not a treatment we normally associate as a treatment. It's not surgery or radiation or some kind of medication.

Nevertheless, we, as urologists and clinicians, are doing watchful waiting in a haphazard manner. No standard way to do it has been established.

We published a paper about two years ago in *JCO* evaluating a group of patients from the military for whom clinicians had recommended watchful waiting. These men were age 70 or less. We found that 80 percent of those

patients dropped out of watchful waiting by four years.

Imagine presenting data like that on surgery or radiation. They would throw us out of the room, saying we were charlatans who did not know how to do this treatment. Yet we published these data on watchful waiting.

It goes to show you that we don't know how to pick patients properly for watchful waiting. It demonstrated that everyone gets scared off when the PSA rises, both the doctors and the patients, and we jump the gun and put the guy on treatment.

None of the physicians here would be willing to go on watchful waiting because of the "C" word and the worry of cancer, even though probably everyone in here has a better chance of dying of a heart attack than of prostate cancer.

DR LOVE: Computerized web-based models have been used in breast cancer to assist with this type of situation. If you go to the Adjuvant! Online website, which is run by Peter Ravdin, one of the fascinating things they incorporate is non-cancer causes of mortality. This is very helpful in older women with low-risk tumors.

I wonder if we really need more research on watchful waiting in prostate cancer, or whether we just need a closer look at the whole health situation of these patients.

DR SCHELLHAMMER: An algorithm like that does not exist for prostate cancer. You might think it would be easy enough to construct, and some pretty thoughtful people are working on it, but it doesn't exist yet.

We look at the tumor and make some estimations, and then we kind of get this gestalt about the host, and then we try to put this together for a reasonable conclusion. It's individualized and, I dare say, from month to month, it's different even for the same physician.

DR LANGE: All these nomograms are good for helping to educate us and for enrolling patients in trials, but I don't know whether it really helps patients. It gives them a false sense of control, which may be good, but does it really make any difference? If your chances of extracapsular extension are 40 percent versus 10 percent versus 80 percent, what is the difference in terms of what you would pick for therapy?

This concept has been over-sold to the patient because they come in with their nomograms and they feel great about having a nomogram, but they're more confused than ever. I think we need to find something that works for the patient — and for the doctor.

DR LOVE: One of the things that must be factored into this is the toxicity of the therapy. When you hear a story like Alan's and he says, "I'd rather die than be treated with this again," you know you need something better.

In breast cancer these nomograms are mainly used to decide about chemo-

therapy, not hormonal therapy. We don't even use these with hormone therapy because the treatment side effects are so benign.

DR SHIMM: To be an oncologist, you have to have the ability to deceive yourself. We do a good job of minimizing side effects to patients.

The work that you've talked about and other people have done, looking at women with the response buzzer, saying, "I'd be willing to have this treatment for a one percent improvement in survival," I think that's really because people don't understand the toxicity of the treatment.

In a sense, they're saying, "Am I willing to take a one percent improvement in survival for free?" And of course, the answer is, "Yes." But I don't think they really understand the toxicity.

Although I'm a radiation oncologist, I practice with a bunch of busy medical oncologists and sometimes they don't always do their work in terms of explaining chemotherapy to their patients. I find these nomograms to be extremely useful for patients. Adjuvant! provides a much more user-friendly printout than, for example, the Parton tables.

Nothing is intellectually more complicated about prostate cancer than about breast cancer, and I suspect that at some point, some smart person is going to come up with a similar sort of nomogram for prostate cancer that will be very useful to patients.

DR LOVE: Lots of assumptions are made in these programs. Adjuvant! contains hundreds of pages explaining why these are just guesses, although the model was recently validated and is very accurate. But getting back to your point,

our group asked breast cancer patients, “Would you go through chemotherapy for a one percent improvement?”

It’s all well and good to say, “55 percent of these women said they would,” but 45 percent said they wouldn’t. That’s a lot, and that means that people see these tradeoffs differently. If the information is placed in their hands, they can make that kind of a decision. I think that the information is out there, it just might not be getting to the patient right now.

In terms of looking at the health threats to a patient, we need to consider the whole milieu that the patient is functioning in, not just specifically the side effects of a therapy.

What else is going on in that person’s life? What’s their lifestyle like? What’s their relationship with their loved ones? All these things affect quality of life, not just the drug and its side effects.

Complementary medicine and supportive care

DR LAWTON: You asked earlier in the day about other things that we could do for patients. From the time I entered this field I thought that every patient with a diagnosis of cancer could use help from a psychiatrist or a psychiatric evaluation.

However, any time you mention psychiatry to patients, especially in the age group I deal with but also in younger patients, the response is, “I’m not crazy” or, “Are you insinuating that I’m crazy?”

The reality is that it isn’t just this diagnosis; it’s the whole body of relationships and families. So many things are involved that only somebody who looks at a person from all of those different perspectives can really be helpful.

How do we encourage the patient to even be willing to listen to someone — a psychologist, psychiatrist, nurse practitioner, etcetera? It’s a huge challenge, but if we can break through, we can help a lot of patients.

DR SHUMAN: Many men would benefit from that type of addition to their therapy, but many men may not want it. As a physician, it is important to pick up on who will and who won’t, and then refer them accordingly.

I probably would not recommend psychiatric consultation for most patients; I think nurse practitioners and psychologists tend to be more practical and more results-oriented.

After I had my surgery, I wasn’t aware of it, but I was angry. My wife pointed it out to me on occasion, and I denied it. She is a pediatric therapist and she located a nurse who specializes in patients with cancer and HIV. I was resistant to therapy, but eventually I began to see that I was angry so I went to see this therapist.

Her approach is focused on meditation, which I wanted to totally dismiss and go back home. I’m not a meditation-type person, but I decided, “I’m here, and I’ll try it.”

Surprisingly, it’s made a huge difference in my life. It became a great way

for me to deal with stress and with my anger, and I think it's had a positive impact on my life — not only from the perspective of having prostate cancer, but just putting things in perspective.

It was something that I needed that I didn't receive from my caregivers — my primary care physician, my oncologist, my urologist. As a patient, I had a different perspective of these caregivers.

When a patient comes into the office and the doctor says, "How are you?" what that question may mean is, "I'm incredibly busy today. I hope you're doing well, and unless it's a really serious problem, don't tell me about it."

DR LOVE: Can you tell us about the meditation? How often do you do it? How do you do it? How long does it take?

DR SHUMAN: It's called guided imagery. Basically, you loosen your tie, take off your shoes, relax, breathe deeply, close your eyes, and put yourself in a pleasant place. Imagine somewhere where you would enjoy yourself.

My first reaction was, "What is this BS?" But I allowed myself to do it, and I could even do it right now. I could close my eyes and be out of this room. I can do it in an elevator. When I'm feeling angry or stressed — which occasionally happens at work — it's incredibly useful. It's something that I learned and continue to practice, and it's made a big difference.

DR LOVE: How long would it take to teach someone to do that?

DR SHUMAN: It took me a few sessions. It probably sounds like self-hypnosis, but it isn't hypnosis. I continued

going back to this nurse for about eight months because I wanted to really establish it as something in my everyday life. She is a nurse psychologist and her visits were incredibly inexpensive.

DR LOVE: I'm curious about the anger. I was recently interviewing a nurse for our oncology nursing series, and she said, "They always send me all the angry patients, because I know how to deal with them."

And I said, "Well, what's your take on angry patients?" She said, "Anger is just another expression of fear." What was your take on why you were angry?

DR SHUMAN: Good question. I did have some fear, as all of us do, but I think it was more than that. One thing I learned from this, which has been incredibly important for me, is to really appreciate and take each day by itself. I do not look forward or think about tomorrow or next week or next month. I think about today and getting my maximal enjoyment out of it.

DR LOVE: Another thing this oncology nurse said was that the angriest people are the attorneys and the physicians and other people who are used to being in control. I'm curious what your experience has been from that point of view. As doctors, people always listen to what we're saying. All of a sudden, we have to listen to what other people are saying. Alan, I see you sort of nodding your head.

DR ROBERTS: One size doesn't fit all. I don't think everybody who goes to a shrink needs to have his head examined, but I do think that every situation has to be taken as an individual situation. One thing

I have learned from my experience with having prostate cancer is that I've become a far better listener and a much more humble individual than I was before. I can help my patients now in a way that I couldn't before.

Nobody knows what it's like to go through what their patient goes through unless they've gone through it themselves. You can try to imagine it, but you can't. Nobody knows what it's like to be castrated until they're castrated.

Our patients would probably profit from more of us having cancer. A humbling experience is a wonderful thing, and as a result, we can take better care of our patients.

DR LOVE: We recently completed a survey of 250 women with metastatic breast cancer. As we began the survey, several of the women started talking about what they look for in their doctor. The patients actually constructed a scale of qualities in their physician. The scale included everything, even sense of humor. We had about 15 different categories and we asked the women to rate the importance of each category using a scale from one to five.

The number one item selected, which was rated as 4.97 on a scale of five, was listening. I doubt that it would be much different in prostate cancer.

DR LANGE: I have always loved the quote from Franz Kafka: "It's easier to write a prescription than come to an understanding with the patient."

In our current healthcare system, writing excessive prescriptions is discouraged. And, if anything ought to come out of these kinds of ruminations, it's a determination to resist that trend. If you go to Canada or to Europe

in the socialized system, the trend is even worse.

We all have nurses and administrators telling us about our profiles and how much time we're spending with each patient, etcetera. I'm worried, because — maybe more so than whether patients are treated with seeds or laparoscopic radical prostatectomy — time is a very important thing.

DR LOVE: I have noticed that things don't change unless people really raise hell. We saw that in breast cancer. One example I can think of was a woman, Rose Kushner — I don't know if any of you have ever heard of her — she was a breast cancer survivor who raised hell about mastectomy back in the early eighties.

She would just walk into medical meetings and interrupt them. It was incredible. People finally started to listen to her. It takes a lot to create change, which is why it's interesting that we have this group of you here.

DR SHIMM: You see the same advocacy in AIDS.

DR MOUL: I don't want to beat up on my own specialty, but part of the problem is that too much attention is focussed on this technique or that technique, rather than on being a comprehensive doctor for the patient.

We're willing to spend all these extra hours to do this robotic or that robotic, which takes a lot more time, and the health system is accepting that, yet they're giving us a hard time about actually spending extra time with patients in the office.

If we reallocate the extra time that we're spending on a four- or five-hour operation, which we could do in two

hours, and put that back into spending time with patients, we'd probably have better-satisfied patients. And we'd make more money, because these days you make more money in the office than in the operating room.

DR LOVE: I'm curious about how your personal experiences have affected the way you take care of patients and what you think about as you go through your day.

Some years ago I had community-acquired pneumonia, which my primary care doc missed. By the time I received antibiotics, I ended up spending a few days in the hospital. One thing I gained from that experience was an incredible appreciation for nurses.

Just the simple things they did were so great when I was feeling miserable. I'm curious how all the different experiences you've had have affected the way you take care of patients.

DR SCHELLHAMMER: I think many of the characteristics have been mentioned with regard to better listening, better understanding, better appreciation, and better communication with family members. I do not initially make it known to my patients that I went through this process, because I don't want to overly influence treatment decisions. I was afraid if I say, "I did this," then all thought processes might just be directed at what the so-called doctor did.

However, after a few meetings with the patient, I say, "I've been through this process, and I really can empathize. And if you have questions, I'm here to answer them, both from the book and from my personal experience." I believe the bond that develops

certainly makes a difference. As folks have already mentioned, it's remarkable how patients like to interact in support of other people, and they find a good bit of healing of their own in supporting you and keeping tabs on how you're doing.

DR MAGRINAT: I liked Alan's earlier comment that, if more doctors experienced a major illness, not necessarily cancer, their patients would do better.

One thing that became clear to me was how unpleasant the little things are that don't go away, such as a Foley — something that in the past, I just put in and I didn't think about it. As a physician, it doesn't bother you; it's nothing.

As a patient, it was irksome for me to sleep with this tube in my bladder all the time. I became very irritable. I was a nasty person. I've become more sensitive to the little teeny things that I paid no attention to before, but the patient lives with 24 hours a day.

For some of them, it's a bigger deal than life or death. They don't worry so much about living or dying, but this little thing that doesn't let them sleep is a big deal.

RICHARD: Having been on the other side, one of the most powerful medicines is a sense of optimism by the person who's taking care of you, and not just sort of brainlessly patting you on the shoulder, but a true, reasoned and genuinely felt sense of optimism. In oncology, we've perhaps shied away from doing that to the extent that we could.

I think surgeons actually do it better. It's a powerful bond that a lot of surgeons have with their patients. Maybe it's an internist/surgeon thing,

but it's a powerful part of taking care of people and it was a part of my experience that was very important.

DR LOVE: Optimism was also extremely highly rated by the patients in the survey I mentioned. Optimism and reassurance, which doesn't necessarily mean we can cure this cancer. It just means a positive feeling about the future, which oncologists have learned how to transmit, even in the worse of circumstances.

Judd, I was thinking about the interview that I did with you when you were talking about what had happened with your father-in-law. What do you say to a urology resident or med student who asks the question, "What can I do for somebody who's beyond all active therapy?"

DR MOUL: Common courtesy, for one thing. I know it sounds corny, but things that we all should have learned as kids can make a difference to patients. Some institutions have such pyramidal training programs that breed such competitiveness and cut-throatness that then translates into patient care.

I'm not saying they necessarily breed all "badness," but they have a tendency to breed some physicians who may have forgotten a lot of the things that our parents taught us. Common courtesy and respect for everyone as a fellow human being — those things go a long way.

DR LOVE: Colleen?

DR LAWTON: When I meet a patient, very often I meet their significant other and sometimes their children. I try to take all of them into consideration. I learned from my own experience that they are important parts of

the patient's support system and treatment.

My mom would call me and tell me things that were going on. My brothers would call me and tell me things that were going on. That has been helpful.

I run our residency program and I teach our residents this all the time — that sometimes the only thing you have to give is TLC.

Fear is an overwhelming emotion and it becomes tantamount in patients who have metastatic or refractory disease for which few options are available. Sometimes just coming in, talking to the patient, and trying to alleviate some of their fears is helpful, even if their fears are, "Am I going to die a painful death?"

You can explain to them that we have all sorts of things to help with pain. That is sometimes enough to really make their day.

DR LOVE: A lot of comments have been made about the issue of the spouse and the different perceptions of the spouse and the patient. One story I hear a lot is the wife wants every possible thing done and is not as concerned about side effects or toxicity. Maybe the patient is not quite so much in that camp. Is that something you've observed in your patients or that you experienced in your own situation?

DR LAWTON: In general, and, at least in my practice, the women (significant others or wives) say, "I want him around. I don't care if he's sexually functioning. I don't care about the litany of side effects. I just want him around."

Sometimes the patients think, "If I'm not sexually functioning normally, or

if I'm not the same person that I've always been, I won't be loved." And that's just a misperception.

DR FAGAN: That's very true, and that happened in my case. My wife is 20 years younger than I am and she's led the whole charge. She's been wonderful, absolutely wonderful.

DR LOVE: Are there times when she wants you to do something more active or aggressive than you wanted?

DR FAGAN: Oh, yes.

DR LOVE: Judd, I'm curious about what we can do to improve patient education.

DR MOUL: Two years ago, the first time you did an audio interview with me, we talked about biochemical recurrence. I actually went back and listened to that recently. I've been doing a lot of traveling between Washington and North Carolina, so I've had a lot of time on the road, listening to the tapes, and you're obviously a good interviewer. You are able to really question people, and that has turned out to be a great educational tool.

After I did that program, I started to think about a similar program for patients. I think the majority of the patients that I'm counseling for biochemical recurrence would actually be able to understand most of what I said on that program.

Some of these modules that you do for physicians are basic enough that we would be able to use them, almost unedited, as patient education tools.

Perhaps you could have one side with the interview module, and on the other side you'd ask questions to bring it down a little further to the patient level.

DR LOVE: What other forms of support can be helpful to patients in terms of nutritional counseling, stress reduction, etcetera? What are some of the things you've experienced that have been helpful to you or that you've seen in your patients?

DR LANGE: I was rather skeptical of alternative medicine strategies, feeling that it took a long time to get out of the medicine wagon and cough syrup era and into evidence-based medicine. After I had my own experience, I found myself walking into an alternative medicine store I had passed many times before.

I went in just out of curiosity, when only a few people knew I had prostate cancer, and I walked out with a couple of bottles with pictures of pretty cherries on them and peaches and whatever — I suddenly understood something that I hadn't before.

We talked a little bit about PSA anxiety — taking the pressure off and giving the patient more control. I think that regardless of its scientific merits, we're beginning to look at this in a scientific way — empowering the patient to do something and not ignoring the "placebo effect," which is a nefarious term to most of us. It's something bad. It's something that we have relegated to the chiropractors and naturopaths. And the question of how we can use it in a way that's honest yet hopeful is intriguing.

DR DEETHS: I don't know what I'm taking, but my wife puts four medicines in front of me every morning. If I don't take them, they are there at night to take. I honestly don't know what they are, but I see the bill every month from the health food store!

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- Offer patients information regarding their prognosis with and without various therapeutic options5 4 3 2 1 N/A
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