

CENTER FOR MIND-BODY MEDICINE
COMPREHENSIVE CANCER CARE 2001:INTEGRATING COMPLEMENTARY &
ALTERNATIVE THERAPIES
PLENARY SESSION: Stress, Support and Surviving with Cancer
SPEAKER: David Spiegel, M.D.

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P R O C E E D I N G S

DR. GORDON: We're very happy to have David here. David, as you can read in his biography, is a professor of psychiatry and behavioral sciences at Stanford Medical School. And he has been almost -- my memory is that almost since residency, David has been a leader in what we have come to call mind-body medicine, that he did some wonderful early work in understanding hypnosis, working on the physiology of hypnosis, on the phenomenology of hypnosis. And he was out there in front very early on. And the textbook that he wrote with his father, "Trends in Treatment," I remember from many, many years ago, very important seminal work in the field of hypnotherapy.

David has also been extremely important to the field as a whole, because he is, in addition to being intellectually open-minded and adventurous, an extremely scrupulous researcher. And his groundbreaking work, which I'm sure hopefully everyone in the room should know about, of a supportive, expressive group therapy for women with metastatic breast cancer -- very, very important, not only because of the results, but because of the care with which David took to create the study and the true scientific dispassion with which he undertook the study. He really wanted to find out, did group therapy make a difference. He never expected, as I'm sure most of you know, the findings that he came of increased longevity for the women in the group. He thought it might improve the quality of life for them, as indeed it did.

And over the years, David has been a leader and an inspiration to a whole generation of researchers and clinicians who are committed to exploring the effects of the mind on the body, the interpenetration of mind and body, and the potential healing power of support groups. And he himself, as he'll discuss in part, has undertaken follow-up studies; that is, studies to replicate or to see whether he can replicate his own findings.

So it's a great pleasure to have David here and to have everyone have a chance to listen to him and be with him and learn about his latest work. David? (Applause)

DR. SPIEGEL: Thank you very much for that generous introduction, Jim. I want to mention, before I begin my formal talk, that Ernst Wynder was a dear friend of my father's and of mine. I had the highest regard for him. He was a charming, passionate man, who made a real contribution to prevention. And Ernst always used to say that his goal was to die young as late in life as possible, and he did that. And I honor him for that as well.

And I know Bill Fair, and I think it's a -- Ernst would smile at the award, and I'm just very pleased that Bill was given it.

What I'd like to do is review with you our research on coping with cancer. This goes back to the late 1970s, when Irv Yalom invited me to co-lead a group he was just exploring of women with terminal illness with advanced metastatic breast cancer. And so I'd like to share with you what we've learned about the process of doing this kind of group therapy, what some of the results are psychologically, and then go into the body part of it, what some of the results have been medically, and some new data we have, suggesting possible mechanisms that might link changes in the mind with changes in the body and surviving with cancer.

But before I begin, in the spirit that Jim has already started, I want to just take a moment to acknowledge the terrible losses we've had in Washington and Pennsylvania and elsewhere.

And as someone born in raised in New York, I found this a particularly painful time. So I just want to take a moment to share with you a few images of what happened.

Since September 11, our laboratory has been working around the clock to do something, because one other line of our research has been acute stress after natural disasters. So we got together and tried to figure out what we could do to potentially be of help. The lab, as I said, worked night and day, and we put together a 15-minute questionnaire that assesses exposure to the traumatic events, symptoms of acute stress, emotion management, coping, social support, and cognitive reorientation. And we posted our web site on September 28.

I am glad and amazed to say that so far, we've gotten 4,600 responses on the questionnaire. We welcome more. We're trying to have data about what puts people at risk in response to the trauma, and also what are the natural buffering factors that help people cope better with this kind of stress.

So the website is coping. stanford.edu, and we welcome any of you to visit the site and fill out the questionnaire, and tell friends and family about it as well. Thank you.

Unfortunately, I've had a convergence of models in my laboratory's research, because as I mentioned, we studied natural disasters. But we've also come to look at cancer as a kind of chronic stress disorder. If you think about it, there are a whole series of stresses that affect cancer patients that are quite inescapable. I had one patient in one of my groups who, when she was diagnosed with metastatic breast cancer, was a Silicon Valley engineer. She decided before she died, she wasn't going to die without doing what she'd always dreamed to become, which was an artist, and she now is teaching art. She came into group one day with this dressmaker's maquette -- and I think you can see here; I ought to use this, so you can see it on both sides -- that she's depicting the damage that was done her body by cancer in the treatment for it. So she had a modified radical mastectomy. She had a TRAM flap reconstruction. She has radiation burns on her chest.

And it triggered, as you can imagine, a rather intense discussion of all of the constant reminders of having cancer, that it's something that is really inescapable, even when the symptoms of the disease itself are rather quiescent.

So there are an ongoing series of stressors that come with cancer that include the existential questions. And even though half of all people diagnosed with cancer will live to die of something else, everybody diagnosed with cancer thinks that it's a death sentence. What we've done in medicine, actually, is convert cancer from a terminal illness to a chronic illness. And so now there are more people than ever living with it and with the constant reminders of the disease.

This involves decisions about diagnosis. It involves side effects like pain, fears regarding the progression of disease, treatment decisions, changes in the social environment, undergoing arduous treatments, reduced physical capacities, changes in family roles. I remind the students at Stanford that -- think about what it would be like to live the life of a cancer patient for a month, even if you didn't have cancer. You'd spend a lot of time in waiting rooms reading stale magazines. You'd be removed from the social environments that give you a sense of well-being and competence. You'd have your life interrupted in many ways. Even without being sick, there are a lot of stressors associated with the disease. This is one patient's depiction of how she felt as a cancer patient.

We're finding, in fact, that a substantial proportion of women with metastatic breast cancer meet diagnostic criteria for post-traumatic stress disorder. So that's what I meant about the convergence of studies; it turns out that people have reactions to cancer that are not so different from the reactions people have to sexual assaults, terrorist attacks, motor vehicle accidents, et cetera.

The red bars here -- this is from a study done by Lisa Butler in our lab -- represent the proportion of our patients that had post-traumatic stress disorder. And it's similar to that, the

yellow bars of rape survivors. So clearly it's not everyone, but a substantial minority of patients meet full threshold criteria for PTSD. And of course, more have sub-syndromal symptoms.

In addition, depression is a common problem. This is sculpture done by a Dutch breast cancer patient to depict her own despair with the disease. And one of the most remarkable things about this sculpture is that it's the only work of art she did in her entire life, which in itself I find stunning. But depression, which you can view in some ways as a chronic maladaptive stress response, occurs in 3 percent of the general population, 6 percent of medical outpatients, 12 percent of medical inpatients, 20 percent of the terminally ill, and 60 percent of those who request assisted suicides. And it's another talk, but I can't resist a comment that before we dispatch people who are in the terminal phases of illness and requesting death, we ought to treat their depression, because even in the very last days of life, depression is a treatable illness. Depressed people are suicidal. And before we think of doing anything like that, first we ought to treat their depression, and second, we ought to reread the Hippocratic oath, because I personally think it's a terrible mistake. (Applause)

Thank you. You know, when patients are given good, compassionate care and pain control for cancer, they don't request assisted suicide. It's a different issue.

Now, what are some of the problems we're having in medicine now? Why can't we address these psycho-social problems? "I'm sorry, Mr. McConnell, your insurance plan only provides for empathetic nodding and a saddened downward glance. There is a \$200 co-pay for any additional words of compassion, not to exceed 40 words or 3 expressions of sympathy or condolence." And unfortunately, I think one of the reasons we're all here is that medicine is not all there; that there is a lot that we are missing in mainstream medical care that was there maybe 150 years ago, but has been taken out of medicine for two reasons: One, the sort of biotechnologization of medicine. We've painted ourselves into a corner in which we think, rather than the oldest adage of medicine being that our job is to cure rarely, to relieve suffering often, and to comfort always, we rewrote our job description in the last century to be that our job is to cure always, relieve suffering if you have the time, and let someone else do the comforting.

Well, the someone else is now becoming us, people involved in complementary and alternative medicine. The average complementary practitioner spends 30 minutes with a patient; the average doctor, 7 minutes with a patient, and going down. And one reason is that we were so smitten with the fact that we could start curing some diseases in the last century, which was a new departure in medicine, I can assure you, we decided that was the only thing to do, and we lost the sense of caring that is part of the oldest tradition in medicine.

This allowed the insurance company bandits who have colonized medicine to treat us as replaceable objects and to demean the practice of medicine. The term "provider" makes my skin crawl. Did you ever hear a mother say, "There he goes, my son, the provider?" I don't think so. (Laughter)

And so what has happened is that the combination of our own desire to be technologically sophisticated and scientific, and the insurance company's desire to demean the professions of medicine, nursing, and other allied health professions, so that they can hassle us more, pay us less, and replace us as if we were replaceable objects, has allowed the humanity to be sucked out of medicine, as you heard from Dr. Remen yesterday, and I think it's a terrible mistake. And I think we've got to reclaim and refine that humanity.

And the fact that the public is so interested in and spends so much money for and goes to so many complementary practitioners, in part, is due to the fact that we've lost this sense of humanity in medicine.

Medicine tends to view alternative medicine like this. It says, "born to cure" on his arm; "heals angels" and "disease sucks" are the three tattoos. And that's not what alternative medicine is either. But we need to get beyond this chasm and learn from one another. And I think the message is loud and clear that patients want a kind of compassionate care from medicine that they haven't been getting.

So what I want to now do is turn to how we do that. How do we deliver that in an age when medicine is necessarily complex, when people who specialize in chemotherapy or radiotherapy can't necessarily devote a whole lot of time to these other sides of healthcare? So it may be that other people have to do it, although there's a lot that doctors can learn just in the manner in which they interact with patients.

There are a variety of individual and group psychotherapies for cancer patients. I want to address just one of them, but acknowledge that there are many ways of providing emotional support for this disease of cancer. I'm going to focus on the supportive expressive model.

Here's one model of group therapy for those of you who have interest in psychoanalysis. Actually, one of the things -- friends ask me, well, you have all these great results for group therapy; why doesn't everyone do it?

And one reason is, if this were a drug, if we got the same results with a drug, there would be a giant industry out there to promote it. The pharmaceuticals industries spend about \$35,000 per physician per year promoting the product. Who is going to promote group therapy? People that make chairs is about the only industry I can think of. So we have to find other ways to train and motivate people to provide this treatment.

There are seven principles underlying supportive expressive group therapy, and I'll go through each of them briefly. Building bonds, expressing emotion, detoxifying dying, reordering priorities in life, fortifying families, clarifying communications with doctors, and teaching them how to better manage symptoms.

First of all, we try to create a new network of social support. And there is a social glue among people who get together for these kinds of groups that is really quite striking. I've been running one group that's been ongoing for 10 years. There are some, of course, many members have died, but there are some who participated in the group for almost the entire length of the group. Their commitment to the research program was to come for at least a year, and they have gone so far beyond that, and there's no reason they would, just because of a research project. They do it because it has meaning for them. They come to care deeply about one another.

And the process of caring about someone else with your disorder is also a statement of your own valuing of yourself. People like me are worth something. They're worth caring about. And unfortunately, as we know, cancer is still somewhat of a stigmatizing disease. People tend to not know what to say about it. Friends don't want to mention the C word or even worse, the D word, and so many cancer patients become isolated.

The nice thing about a group is that the same thing that isolates you from the rest of the world is your ticket of admission to a support group. People find that they have problems in common; that people get weird on them, not because they forgot someone's birthday, but because people don't know what to say to someone with cancer. And everyone in the room has had the same experience. So it normalizes situations.

It also helps them find meaning in an otherwise meaningless tragedy. There is nothing good about getting cancer. But if you can use your experience with it to help other people get through it better, then something genuinely good has come out of a terrible situation.

You may have noticed that the people of Oklahoma City made an award to the people of New York City. Now, you might ask, "Why would they revisit their own trauma with the Murrah Office Building bombing?" Because they want to feel that something good has come out of the terrible tragedy they suffered, and they want to offer something to the people of New York. That's a human attribute that we can mobilize and make use of in support groups. It's been called the helper therapy principle.

There was a social worker named Frank Riesman in New York who undertook a strange experiment. He had children in primary school who couldn't read. And the typical thing is to give them more tutoring, and they don't learn any better, and that's the end of it. Well, he took sixth graders who couldn't read and gave them the job of tutoring second graders who couldn't

read. And the results were very interesting; the second graders still weren't reading any better, but the sixth graders were. Simply putting them in the role of teaching someone else to read helped them improve their own reading skills.

We know that in medicine. We feel better about ourselves to the extent that we can help other people. Why should we confine that to the profession? Why wouldn't the same principle apply to patients? And indeed, it does in support groups. One of my patients was a frustrated poet. By the time she died, she published two books of poetry. This is one. "Never ask us why. Most of us don't know, and those who do won't tell. So we build you a reason, a barrier to shut out any probing of our scars, self-inflicted or not. If you will love us a little and let us weep when we must, we may find out who we are."

The second principle in this group is expressing emotion. That's why we call it supportive expressive. It's very important. We teach the leaders just to follow the affect. You don't follow the content in the room, follow the affect. And in this way, our approach is rather different from the cognitive behavioral methods that grew out of the very effective treatment for depression. For people who are just depressed, the problem is the depression, and you want to use therapy to help their cognition pull itself out of the mire of depressive reiteration of how bad they're feeling. However, when you have breast cancer that's advanced to other parts of your body, you have a reason to be at least sad at times, if not sometimes depressed as well. And we're convinced that expressing the emotion, rather than trying to suppress or alter it, is the best way to deal with it. So we encourage patients to face feelings directly.

When you experience your sadness or your fear or your anger in a supportive context, you're combining the emotions of the sense of being accepted and cared about with the sadness and the fear. And that can transform the emotions, as we've all felt in the last month, as we've shared our anger and our sadness and our pain about what has happened in this country. It feels different when you share that with other people who have the same emotional context. So it creates closeness, rather than leaves one feeling isolated. It is a different thing to feel scared that you will not live to see your daughter graduate from high school at 2 o'clock in the morning alone than it does to discuss it at 1 o'clock in the afternoon with a group of other people who have had the same kinds of fears. So that ability to share emotion is a crucial part of it.

Many cancer patients are imprisoned by this notion that they should look happy all the time. And that is not Bill Moyers's "Oil of Gladness," I should add. They feel that they have to put on a happy face. And there are some in the alternative medicine world and in popular psychology who say that if you think, you know, bad thoughts, if you think that somehow the cancer's going to progress, you're going to make it happen in your body. I'm here to tell you, that is not true. People don't get cancer because they need it emotionally. It is a terrible thing to lay a guilt trip on cancer patients. (Applause) thank you. We get cancer because we're biological beings, not because we have some psychological conflict.

I had a mother call me from New York years ago, saying, "I have a 6-year-old with leukemia. And I called up one of these cancer support programs and told them that. And they told me, 'Every child with cancer is an unwanted child.'"

And she said, "Could that be true?"

And I said, "You can tell them to go to hell for me, please."

So it's awful thing. You know, we want to be in control. And people go for this stuff, because we would all rather feel guilty than helpless. Helplessness is the worst thing to deal with, and people will buy it, because it gives them a fantasy of control over something they don't fully control, even if it makes them feel lousy.

So we have to be clear that facing the worst is in no way yielding to the cancer. In fact, we have evidence that it really helps people cope better with the cancer. We tell patients, hope for the best, but prepare for the worst, and we think that's the best way to deal with this illness.

So one of my patients started to cry. And her husband said, "Don't cry, it'll make the cancer spread." And the members of the group decided to label that the prison of positive thinking.

In fact, Cheryl Koopman in our lab looked at cancer patients who try to suppress emotion, and what she found was that those who do on a scale called a Cortauld Emotional Control Scale, the green bars here, actually were more anxious and depressed than those who didn't. So despite their tendency to underreport their distress, they were more anxious and depressed. So it just doesn't work.

Thomas Jefferson said, "When angry, count 10 before you speak. If very angry, count 100." Mark Twain said, "When angry, count four. When very angry, swear." Mark Twain has already been quoted at this conference to good effect, and here's another one I agree with. Shakespeare put it differently. In Macbeth, he said, "Give sorrow words. The grief that does not speak whispers the off-wrought heart and bids it break." And Shakespeare was one of the early practitioners of mind-body medicine here; he clearly felt that not dealing with grief psychologically could have physical repercussions, and I think he was right.

Janine Giese-Davis in our lab has been studying the extent to which we do this in our groups, and how it contrasts with other kinds of support groups. And what she's found is that, in fact, our supportive expressive groups involve a considerable emphasis on expressing true feelings. The wellness community with whom we're collaborating in research does to a similar, but not quite as great, extent, as does the cancer support community. But notice that the lecture discussion groups and self-help groups do that a lot less.

Handling the strong affect is a difficult thing to do. You have to make patients feel accepted and understood. They're talking risks. You have to manage the emotions in the group as a whole. It's something that requires skill, and I'm not surprised that less of it happens in groups that are self-help, rather than leader-led.

The third theme is detoxifying dying. It may sound like a strange thing. And I'll tell you that in the 1970s, when we started this, many oncologists were afraid that we'd make patients worse, that we'd demoralize them. You know, you have a roomful of women with metastatic breast cancer. Some are going to die, and it'll scare the hell out of the others; that was what we were worried about, frankly.

But if you think about it, death is not a novel concept to a cancer patient. I had occasion to present this work at Stanford some years ago to the Dalai Lama, who is just a wonderful man, and he's got a combination of tremendous intellect wisdom with a kind of childlike playfulness and joy in life that is really remarkable. And I presented this to him. And I asked him why, from his Buddhist perspective, he thought it might be helpful rather than hurtful for women in a group to confront one another's death.

And he looked at me and thought for a minute. And then he said, "I have a busy travel schedule." And I thought, we're not communicating here. And his English is very good. And he said, "And it makes me anxious. And when I get anxious about it, I call over one of my assistants. And I say, 'what am I doing for the next 3 days,' and he tells me. And then I feel better." He said, "That's the way we Buddhists feel about death. We make it familiar to us, and it becomes else frightening."

So he got it exactly right. We are so death-phobic in this society that we never deal with it. Very few people -- many Americans have not actually seen anyone die. How many of you have seen someone die literally first-hand? Boy, you're an unusual group, but there are still many among you who have not.

And so I think part of this -- obviously, death is frightening in many ways, but part of this is simply the unfamiliar. One of my patients in the group said, "You know, I watched a friend of mine die last week, and it was terribly sad, but it wasn't that ugly. I realized that I could do it." So just making one familiar with it is a way of detoxifying death.

In fact, most people with cancer that I've talked to are much more afraid of the process of dying than they are of death itself. Either their spiritual beliefs comfort them about what happens after death, or their existential point of view is that it'll be our problem, not their problem, after they've died. But what they are worried about is being in pain, not having control over treatment decisions, being isolated from loved ones. And that's something you can do something about.

When one of our members died, another made these cards that she distributed to the group. "Dear Eva, whenever the wind is from the sea, salty and strong, you are here, remembering your zest for hilltops and the sturdy surf of your laughter gentles my grief at your going and tempers the thought of my own." And the last line, I think, is particularly important.

Another woman said, "What I found at the beginning of the group is a bit like that fear you have standing at the top of a tall building or at the edge of the Grand Canyon. At first, you're afraid to even look down. I don't like heights, but gradually you learn to do it, and you can see that falling down would be a disaster; nonetheless, you feel better about yourself, because you're able to look. That's how I feel about it, death in the group. I'm able to look at it. I can't say I feel serene, but I can look at it."

In fact, there's something reassuring about grieving the deaths of others, because you experience death the way your friends and family do your impending death. You understand from a different point of view. And in feeling your own grief at someone else's loss, you can feel the grief others will have about yours, and that is actually deeply reassuring.

Plus, these discussions are not always grim, surprisingly enough. One woman was having a rather difficult discussion with a group about arranging for her remains to be buried so her husband didn't have to do it. And she called Skylawn Park, which is a beautiful cemetery overlooking the Pacific Ocean, and asked what it would cost. And they quoted her some astronomical amount of money. Real estate is very expensive in the Bay area.

And she said, "Well, you know, actually, I represent a group of women who are looking for a place to be buried." And there was a long pause, and the woman said, "Skylawn Park does not offer group discounts." And they all had a good laugh about it. (Laughter)

Now, you know, this is a group of women with metastatic breast cancer. And we've seen that time and again, that if you can face the worst and deal with the sadness and the fear, you can also, at times, have a good laugh about very difficult situations.

We find in Dr. D.C. Davis's assessment of the content of what we're doing, using videotape analysis, that in fact, a supportive expressive model addresses most frequently existential topics, followed by the wellness community and then other groups. And you can see that there's relatively less of this in lecture discussion and self-help group. So this is just an empirical way of saying that we're actually doing differentially what we claim is different about the treatment.

Now, one of the things that you discuss when you're talking, when you're willing to face your death, is how you live the time you have. And in fact, the old existential adage that ---- interested in this in the beginning is that you don't really live authentically until you face the contingency of your life. People reorder their priorities in life.

One woman in the group said, you know, my daughter was three units shy of graduating from college with her class because she'd been coming back to the West Coast to visit me with my illness, and the dean wouldn't let her take the units. Now I called her up, I called the dean up, and I said, "I want you to let my daughter graduated with her class." And the dean said, "We have our rules. I can't do this. Why should I?" And she said, "Because a year and a half ago, my oncologist told me I have a year to live with breast cancer, and I want to be alive to see my daughter graduate."

And there was this dead silence. And the dean said, "Oh, you're so brave, you're so wonderful. How many units did she want to take? What can I do?" And her daughter called her up and said, "Mom, what did you do the dean?"

I am glad to report that she lived to see her daughter graduate with her class from college and lived to see her graduate from law school before she died. Now, this is someone who took very seriously the imminence of her death, but who decided, if it was close, she was going to live her life the way she needed to live her life and reorder her priorities. So politeness got low down on the list. Interfering with her daughter's school got low down on the list, and she did what she needed to do.

So we find that's a very useful thing, and we do what we call an Orpheus exercise -- Jim Bugenthal developed this -- where we have people close their eyes, make in their mind a list of attributes who they are -- teacher, runner, lover, scholar, whatever it is -- rank-order them in terms of importance, and then imagine that they can no longer be the least important one, and ask themselves the question, "Who am I?"

And so we have some painful, difficult discussions. But it's a way of getting people to face what they're losing as attributes and ask themselves the question "Who am I" to reorder their own inner priorities in life.

However, not everyone gets it. "I'm sorry, Mr. Rainey, our tests show you have 2 weeks to live." And he says, "Can I take them in August?"

Cancer affects families, as well as patients. And we've run groups for family members as well. They often don't know what to do. And there are, of course, gender differences as well. Men tend to want to fix things. The model of a problem for a man is the broken muffler on the car; you know, just take it out and replace it. And women with breast cancer want people to understand and accept how they're feeling. And the more husband helpfully tries to fix it, the angrier she gets.

One man in a group said, "My wife was a computer programmer, tremendously energetic woman, was lying on the floor of the living room crying, because she was so weak from chemotherapy she couldn't stand up. And I kept trying to make her feel better and cheer her up and offer her suggestions, and the more I did, the angrier she got at me. And finally, I gave up completely. I knew I'd failed. And I just got down on the floor and cried with her." And that turned out to be the right thing to do, that he was just there sharing her experience of frustration, rather than trying to talk her out of it.

And so those are things that men in groups talk about. One man said, "This is a place where I come to feel better about feeling bad." They can see other men going through things that lay ahead of them. It's painful and difficult. They come to realize that they really will lose their partner, but they also see that it's possible to get through it. So we find that it's very important to help families share roles, be flexible about the roles that they have, and deal with their own emotions in the same way the patients do.

The sixth theme involves dealing with doctors. Patients feel punished by their doctors. It is a tough thing to be an oncologist, because, unlike a cardiologist -- you know, the minute you go into an emergency room with a heart attack, you love your cardiologist because you have this crushing substernal chest pain. You can't breathe. And a few minutes later, you're breathing; the pain's better; and you love this guy or woman forever.

With cancer, it's exactly the opposite. You come in with a little lump or a little bleeding. You feel fine. And you become miserable as a result of the words of the doctor. And the treatment through most of cancer care makes you feel worse than the disease. As Susan Love says, "It's slash, poison, and burn." It's only toward the end of the illness that the treatment actually makes you feel better.

And so there's a kind of behavioral paradigm set up with oncologists that is very difficult, in which you tend to feel punished by your doctor, and you tend to withhold information, because, you know, the last thing I said was I had a little lump and looked what happened; I'll be damned if I tell him anything else about me.

And so you have to overcome that kind of initial negative reinforcement hurdle in dealing with patients. And we encourage patients to insist on clear communication with their doctors,

using plain language. If you have a list, give it to the doctor at the beginning, not the end of the session. Bring a friend with you. We have one very good, but very rigid oncologist at Stanford who gets nervous when he sees two of his patients coming for the appointment of one of them.

And when you're so emotionally involved, it's very difficult to get clear information and keep it clear in your mind. At Stanford, for important diagnostic consultations, we audiotape the interview so that patients can sit in the peace and quiet of their home and listen to what was said another time.

We encourage patients to take control, to participate in and share in decision making when that's possible in medical care. There are a number of studies that show that cancer patients who participate in the choice -- for example, about lumpectomy versus mastectomy for breast cancer -- are happier with the outcome, regardless of which choice they made. In fact, that is more determinative of adjustment 2 years later than which choice they made, which is very surprising. So participating in control over treatment decisions is very important.

And the third thing I've talked about earlier is the sense of caring. Patients want and need their doctors to care about them. They read the emotion, the relationship with the doctor, as being as important in their outcome as the content of what the doctor says. You can tell someone very good news in a sort of dismissive way that makes people feel lousy, and you can give people bad news in such a way that they feel cared about, understood and appreciative. One of my patients said, "Tell doctors, tell me anything you have to tell me. Just hold my hand and look me in the eye when you do it." And I think that's an aspect of medicine that we have drifted far too far away from. It's another image of a patient and how she felt about her cancer.

So we think that good coping with distress of cancer involves acknowledging rather than avoiding a crisis; seeing problems on a continuum, rather than all or none; seeking rather than avoiding information; bearing and sharing negative emotion rather than suppressing it; seeking social support rather than remaining isolated; developing active responses to problems rather than remaining passive; and speaking and considering treatment alternatives.

Now, the seventh thing we do is, we teach people to control symptoms like pain using self-hypnosis. Hypnosis is just a form of highly focused attention, like getting so caught up in a good movie or a play that you forget that you're in a theater watching a movie or a play, and you need to reorient yourself when it's over. We do it naturally all the time. You may hopefully have not been paying much attention to the sensations from your bottoms touching these wonderful chairs here while you've been listening to me, until I called it to your attention. We do it naturally. You can learn to do it in a more structured way if you're dealing with problems like pain as well. So hypnosis is just a heightened form of focused attention that we can use to alter our perception of problems like pain and anxiety.

This is a diagram from Ronald Melzack's work showing that not just competing input from the periphery, but descending influence from the cortex can modify activity in the pain processing centers in the brain stem, as you see in the next slide here. I think you can see that the baby's getting the shot and the father's the one who's in pain. (Laughter)

This is my daughter's depiction of what I do. She says, "My dad hypnotizes people and makes them want to live longer." And you see a particularly successful clinical example. (Laughter) This doesn't represent her current level of artistic ability.

So we taught people a simple self-hypnosis exercise. And if you want, we can take a minute and I'll give you just a taste of what it's like, for those who would like to do it. Just get comfortable. Look up. Close your eyes slowly, take a deep breath. Breath out, eyes relaxed, body float. Imagine you're floating somewhere safe and comfortable, a bath, a lake, a hot tub or just floating in space. Imagine you're floating right down through the chair. Because it's here in a bath or a lake or a hot tub. And if you have some discomfort, imagine that part of your body is warmer or cooler or tingling. It feels better. Imagine you're immersing it in warm water or rubbing ice or snow on it. And let the warmth or coolness or tingling just filter the hurt out of the pain. Each breath deeper and easier. Just filter the hurt out of the pain. Each breath out. Let a

little more tension out of your body. Now take a moment to reflect on what this feels like to you in a private sense. And then when you're ready, bring yourself out by counting backwards from three to one. On three, get ready, two with your eyelids closed, roll up your eyes. And one, open. Ready, three, two, one.

Everybody back with us? I don't see anyone floating near the ceiling, which is a good thing. So that just gives you a little taste of how quickly and easily you can shift your attentional focus and use that cognition to alter perception.

We found in our original study that women who did this in the support group had half the pain in the treatment group that the control patients did on the same and very low amounts of medication. For those who are more interested in the treatment, our book is "Group Therapy For Cancer Patients." Catherine Classen is the co-author. It was published in 2000 by Basic Books. No good home or office should be without one.

I want to turn now, in the last few minutes, to a review of some of the data we have about the effectiveness and mechanisms of this treatment. I'm going to skip through some of the demographic information. This is from our new replication trial, funded by NCI and NIMH.

What we found is that women who went through supportive expressive group therapy had a significant reduction in their impact-of-event scale scores, the yellow line here, versus control patients. So the reduction was significantly greater in the treatment group.

So despite confronting death, despite watching other people die, despite sharing the distress that the group as a whole felt about that, our patients had less post-traumatic symptoms than control patients, and we had similar findings on the profile of mood states, which is a general measure of anxiety, depression, fatigue, confusion and so on. This confirms our earlier findings and those of others, and these data were published in Archives of General Psychiatry earlier this year.

Janine Giese-Davis has a paper that's coming out in the Journal of Consulting and Clinical Psychology, showing that we also reduced patients' tendency to suppress emotion on a scale that measures emotional suppression. This the treatment sample; this is the control group. So we are actually changing peoples' style, emotional style, and teaching them to be more open about their emotion. And that's associated with a reduction in distress as well.

And we've had a similar effect on people's tendency to be hostile, but not in an constructive way, in the group. We have increased patients' sense of emotional self-efficacy. We had developed a scale that measures how well they feel they manage their own emotions, and we're able to show a significant effect on that as well.

We've implemented this program in a multi-center trial as well. We trained therapists to focus on the here and now, on bringing problems into the group on emotional expression, on supportive group interactions, being sure everyone gets a chance to talk, no one is scapegoated, and finally, on active coping, teaching patients to find some aspect of any problem that they can do something about.

This was done in cooperation with a community clinical oncology program. This just shows that our therapists were in fact able to learn effectively what we had to teach them. We defined high-distress patients with a cutoff score on the profile of mood states, and we were able to show that those with high distress benefited significantly from the group. Those with low distress didn't have much room to improve. But we couldn't show any effect of the group. So we and Pam Goodwin presented yesterday some similar evidence found that it's the patients who are significantly anxious and depressed, who seem to benefit the most.

(Tape interruption)

DR. SPIEGEL: -- Lucy says, "My body just doesn't seem to want to do what my brain tells it to," and Charlie Brown says, "I can understand that, my body and my brain haven't spoken to each other in years." (Laughter)

What I want to do is -- and that's been the state of modern medicine, and Jim and his group have certainly worked long and hard to correct that. He mentioned our study in The

Lancet, showing a significant survival advantage, to our surprise, for patients who got a year of supportive/expressive group therapy. By 48 months, all the controls had died, and a third of the treatment group were still alive. I was very surprised by that finding.

This is the state of our current study. We have 80 percent overall mortality. The red line here, these are the treatment and control lines from the earlier study. So, you see, we're not at the point where we can adequately analyze the possible effect of psychosocial treatment on survival in our new study. When we get to 95 percent mortality, we will, and I'm glad to see that our patients now are doing better than our patients did in the 1970s. Breast cancer treatment has in fact improved.

There are now six studies, five published, showing that psychotherapy has an effect on survival time. This is very surprising. I didn't expect it in ours, and I didn't expect that others would find that -- with a variety of cancers, two with breast cancer and some with lymphomas, melanomas, and GI cancers. So there is other evidence from other laboratories that psychotherapy seems to have an effect on survival time.

However, there were also five studies, four of them published, one presented here yesterday by Pam Goodwin, that do not show this effect. Pam's was an excellently conducted trial of supportive/expressive group therapy for 225 women at 7 sites in Canada. She found, as did we, that the treatment had a significant effect in reducing anxiety and depression and in reducing pain. So clearly they did the therapy well, but they found no effect at all on survival.

Now, why the difference? We might be wrong. There were differences in the samples in Pam's study that might account for it, but I don't think do. It may be a cohort effect. Breast cancer treatment has changed dramatically. It's much better, and some of the variance that we may have effected with group therapy in the '70s may now be effected by hormonal therapy and better chemotherapy in the '90s.

Also, the psychosocial environment has changed substantially. It's not as easy to be left alone with your cancer, to be isolated with it, as it was 20 years ago. So we may have been repairing a defect then that is now less evident, because everybody is getting better supportive care. We don't know; we clearly need more studies. There are some that support the hypothesis, and clearly, there are some very well-conducted studies that do not.

What are possible mediators of survival effects of managing stress here? My stress, for example. (Laughter)

Well, we have one candidate, and in the final part of my talk, I want to mention it. This is work that was led by Sandy Sephton in our lab, who is here. She's now at the University of Louisville, and she's here with a number of members of her excellent lab there.

There are a number of possible pathways that could link psychosocial intervention with some delay in disease progression. One of them that's gotten a lot of attention, of course, is the immune system. And there is evidence suggesting that certain aspects of immune function, like natural killer cell activity, may well be related to the progression of breast cancer, and we investigated that. But I'm not going to talk about that now. I'm going to talk about data on the endocrine stress-response system.

The endocrine system involves a kind of second-stage reaction to stress. The first is the autonomic nervous system, and then along comes the brain, triggering the hypothalamus to secrete CRH to the anterior pituitary; it secretes ACTH to the adrenals; and cortisol is secreted into the blood. It mobilizes glucose to prepare you for the flight-or-fight reaction. It also suppresses other activities, like immune function. So the body shifts into acute response mode and away from chronic response mode. But then this system is tightly regulated -- there it goes again -- so that once cortisol levels start to rise, the system starts to shut off the feedback here that turned it on. So you have a system that should turn itself on when it needs to, and turn itself off when its done.

However, Bruce McEwen -- something happened to this slide, I don't know what -- points out that there's a concept of alostatic load, in which the body is overwhelmed by repeated,

chronic, even mild stressors. And that can have adverse health consequences in a variety of ways involving metabolism, as well as glucocorticoid stress response.

The way we process stress depends on our position in the world. The big fish says the world is just; the middle fish says there's some justice; the little one says there's no justice in the world. And being stressed or perceiving your situation as a stressful one can lead to dysregulation of this cortisol response system. The white line in the middle is a normal stress response curve. The green line at the top is what you see in people who are depressed. So whereas, normally, your cortisol levels -- we all know from recent experience that waking up is a daily stress task, and our cortisol levels tend to be four or five times as high in the morning as they should be as they should be -- as they are in the evening.

If you're depressed, your cortisol levels are high all the time. People with post-traumatic stress disorder tend to have chronically low -- a kind of burned-out system that has been overused at one point and is now burned out. In both cases, they have lost the wide diurnal variation in cortisol.

And there has been evidence of altered circadian rhythm cycle in patients with cancer. In our current study, we looked at 104 women with metastatic breast cancer, collected saliva samples -- you can reliably measure cortisol in saliva at 8 a.m., 12 noon, 5 p.m., and 9 p.m., and log-transformed the scores so we could calculate a line with a slope and an intercept.

Here you see the blue curve, a normal cortisol curve. But about two-thirds of our sample had abnormal curves, either just flat lines or actually increasing throughout the day. And when Sandy Sephton took a look at these data, she divided them into relatively normal and relatively abnormal for purposes of display, and she found a significant difference in survival time. So the patients with the relatively normal curves -- the blue line, here -- actually lived significantly longer over the ensuing 7 years than patients with the relatively abnormal flat cortisol curves. This was published in the Journal of the National Cancer Institute last year. There's been another study as well in patients with colorectal cancers from another group that shows the same thing.

So we think that dysregulation of diurnal variation in cortisol is a predictor of early mortality with breast cancer, of more rapid disease progression. And it is associated with stressors -- for example, marital disruption. The women who had lost a spouse, either through widowhood or divorce, had these relatively abnormal patterns. Those who are married had relatively normal patterns. And those women who had never made the mistake of getting married in the first place also had relatively normal patterns. So it was loss of social support that seemed to make the difference.

And there have been a number of other studies that suggest that aberration in cortisol is associated with advancing cancer. And one study from the Miami group that group therapy for breast cancer patients tends to normalize cortisol values. So we think the endocrine stress-response system is a very important area to look at, in terms of understanding more about advancing cancer and the mind/body relationship in how stress and stress management may affect the rate of disease progression.

I want to acknowledge and thank my colleagues and collaborators at Stanford, who are a wonderful group of people, as well as the patients who have given very generously of their time and feelings and personal lives to help us understand more about how to help people cope with the stress of cancer. Here is the lab group. They're just a terrific and dedicated group of people, and I feel very fortunate to have them working with me.

I want to also mention that, since 1998, we've had this complementary medicine clinic at Stanford, which we recently renamed in the spirit of this conference: The Stanford Center for Integrative Medicine. We welcome inquiries and visits from you about our services, which include group therapy, hypnosis, massage, mindfulness-based stress reduction. We have a cancer supportive program that is directed by Ernie Rosenbaum -- oh, here we go, here are the rest; I wondered where they hid -- that involves nutritional counseling, yoga, tai chi, and

informational lectures about how to cope with cancer. We have acupuncture, biofeedback, and the clinic now has 750 visits a month. It's a terrific team, and I think we have opportunities to study how combinations of complementary treatments can work in conjunction with medical care. Let's see here. Okay.

Shakespeare said, "When we our betters see bearing our woes/we scarcely think our miseries are foes;/the mind much suffereth doth or skip/when grief hath mates in varying fellowship." I think it's a lesson for us all in how to deliver medicine that is both effective and compassionate for patients. But the mind-body model can be followed a bit too far.

He's saying, "What happened here, Sergeant?" And he says, "It's a placebo overdose. We're pretty sure he only thinks he's dead."

Thank you for your attention. (Applause)

DR. GORDON: Thank you, David, for the presentation and for all your wonderful work. (Whereupon, the PROCEEDINGS were adjourned.)

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