- 00:00:05 AMOLA SURYA: My name is Amola Surya, and I will be moderating today's webinar.
- O0:00:10

 I'd like to introduce this morning's speaker, Dr.

 Shakun Malik, head of the Thoracic Head and Neck

 Cancer Therapeutic Clinical Investigational Branch of
 the National Cancer Institute.
- 00:00:21 Dr. Malik will discuss her personal experience as a practitioner and what she identifies as the most challenging issues in cancer prevention and treatment.
- O0:00:31 At this time, all participants will be in listen-only mode. Please note that this webinar is being recorded. If you have any technical difficulties or questions, please enter your question in the chat window so we may help you.
- 00:00:45 I will now turn the call over to Dr. Malik.
- 00:00:50 DR. SHAKUN MALIK: Thank you very much. Thank you.

 Can you hear me?
- 00:00:55 AMOLA SURYA: Yes, we can hear you.

- O0:00:57 DR. SHAKUN MALIK: Oh, okay. Thank you. Because it [came something I had to] -- Okay. This is Shakun Malik, and thank you for asking me to give a presentation.
- O0:01:04 So I am going to be discussing today -- you can go to next slide -- what are the challenges for patients and their families, as well as the physician, when a patient is diagnosed with lung cancer. Next.
- O0:01:24 So to give a background, so I'll give a little bit of background about lung cancer, then I'll go to what the diagnostic challenges are and how -- if I look at it from patient perspective, and, then, the physician's perspective.
- O0:01:44 And then how the patient gets treated, how we do the treatment, selection challenges. Again, I will divide it into two sections. One will be the patient, what the challenges they have and then I'll go to what the challenges the doctor faces. Next.

- 00:02:07 So, unfortunately, lung cancer is still the leading cause of cancer death, not only in the United States, but worldwide.
- 00:02:19 This is a cancer where patients die more than breast, colon and prostate together, but this is one of the deadliest cancers.
- Unfortunately, also, that most of these cases -- about 70 percent -- are diagnosed later stages, and so we don't, at later stages, have any therapies at the current time to cure them.
- 00:02:49 We can treat them, and there has been a lot of progress made in the later stages. We have now targeted therapies, (inaudible) therapies. We have just recently launched physician medicine trials for lung cancer, which are two of them, but, still, we cannot cure these patients. And approximately about 170 percent -- I'm sorry -- 170,000 patients are diagnosed in U.S. each year.
- 00:03:23 So here on the right side is a pie which gives you what stages. This is for (inaudible) lung cancer. As

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you see, that Stage I and II are only 16 or 17 percent, and, as we go higher, most of the patients are in III and IV. Next.

- O0:03:46 So when we, in general, talk about lung cancer, most of the trials, you will note that it is divided in two sections, which is now an [old thing]. I will discuss a little bit more about this.
- O0:04:01 So we used to decide that lung cancer was just small cell and non-small cell, and small cell actually is decreasing in incidence which is about 13 percent.

 Used to be up to 18 percent, but that [stuff], it was called non-small-cell lung cancer.
- 00:04:17 But, now, with the precision medicine, we actually have many, many small subsets of the lung cancer which are divided based on genetic mutations or in the tumor, in the patient's tumor.
- O0:04:34 So just to keep, you know, the talk what we are going to focus on that I have not focused on it on this talk, but if you have any questions or anything that you will want me to discuss after I finish with

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presentation, feel free to ask or please interrupt me in between if you need to ask me any questions if I'm not clear on something. Next.

- 00:05:01
- So, again, this -- I mean this -- just this slide just depicts a graph of survival, and we -- from Stage I, you know, we can -- Stage I is the smallest lung cancer that one can find, and it includes mostly patients that, you know, now we have the CT screening, so you may find Stage I lung-cancer patients, and surgery is still the main [still] how we can cure these patients.
- 00:05:39
- But as you see that, you know, even in those patients, we cannot cure everyone. There is still only 60 percent chance of survival in five years, so which means about 30 to 40 percent of these patients as well will recover within five years. Next.
- 00:06:03
- I think you had a webinar on smoking cessation. I think I saw some of your webinar, so you know that the smoking is the main risk factor. So 80 percent of the lung cancer that's in men are from smoking, and in women, and there are other cancers that are associated

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with smoking as well. So we all know that smoking is the major risk factor for lung cancer. Next.

00:06:34 What is interesting in this graph is that, you know, it takes a decade or more once a patient or people stop smoking to see a decrease in their lung-cancer

incidence.

- O0:06:48 This is just showing that, in the beginning, how people started to -- We found that, you know, this is one of the factors that patients can develop lung cancer. So as tobacco use decreased in 1900, we are seeing a decrease in lung-cancer patients a decade later, and it is -- Luckily, we are seeing more and more decrease in the incidence of lung cancer. First, we saw it in males and now we are seeing it in females as well. Next.
- O0:07:30

 You know, sometimes, other -- What are some other risk factors in addition to smoking? There are various factors that have been -- some studies showing them, and some are -- You know, there is no [theory] out there whether yes or no on these, but what -- some of

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the things that are of interest or have been thought to be associated with lung cancer are asbestos.

00:07:57 We know asbestos is associated with Mesothelioma, but if a patient has asbestos exposure and has smoked, they have a tremendously high chances of getting lung

cancer.

- O0:08:10 Radon and others like chromium, nickel, arsenic. So there is many interesting data on diet and the vitamins. So there have been some studies, for example, with beta-carotene, and patients -- There was a randomized trial of patients who were smokers and they got beta-carotene or did not.
- O0:08:33 And, similarly, there was a study of selenium that was presented (inaudible) a few years ago where they took selenium. So both the studies, actually, betacarotene showed that -- study showed that if a patient took beta-carotene and were smokers they actually had a higher incidence of lung cancer, so that study was (inaudible) as well as the selenium.

- 00:08:58
- Another interesting data that is evolving at this time is the genetic and the [familiar] factor. It has been noticed that in some patients the patients develop lung cancer very early. Earliest I have seen in my practice is 28 years old, but I know from some of my colleagues the patients have been 18 or 19.
- 00:09:24
- So we have started looking at (inaudible) genetics to see what was the reason why these patients developed lung cancer. In fact, we were just discussing one of the patients yesterday when they actually found one of the genes that was (inaudible) gene. So these factors are still being looked at and are still evolving.
- 00:09:50
- Another interesting thing has been hormones. So hormones [having] -- Some of the investigators are working, and there are some estrogen hormones that have been found in lung cancer. Now, they are different than the breast cancer hormones, so that's another field where people -- investigators are looking at. Next.
- 00:10:16
- So the patient can present with any kind of signs or symptoms. Unfortunately, lung cancer, or I should say

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lung, does not have pain [fibers] around it. So you don't feel pain 'til the tumor is very large or it penetrates in the (inaudible) wall or in the pleura, which is the lining of the lung, and then the patient starts to get pain.

00:10:40

And the cough doesn't come 'til the -- unless it obstructs the central part, which is the bronchus. So that's one of the reasons why most of these patients don't have any symptoms, and by the time they develop symptoms, they have advanced-stage disease.

00:11:00

But they can present with any of these symptoms, and, in fact, you know, some of the patients in my practice would present with headaches or they will go to neurology, will be in ICU, and they will have a [resection] of a mass in the brain, and we later would figure out that it was lung cancer. So they can present variety of -- with variety of symptoms. Next.

00:11:26

So the treatment -- This is a treatment outcome by stage, and I put the slide here because next I'm going to talk how difficult it is to make the -- how important it is to make a point that the -- it's very,

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very important to stage the patient properly, and the staging can be -- proper staging can be kind of a tedious or difficult job if you don't work on it in a methodical way.

- O0:11:56 So surgery is still the treatment of choice for Stage
 I and II, and as you saw there, the (inaudible)
 survival decreases with the stage.
- O0:12:06

 But when a patient develops Stage III, which is -which [I'm going to] also again discuss, is that when
 it goes to (inaudible) a lymph node, you see that the
 therapy changes. It goes to (inaudible) the modality
 therapy, which is surgery. It could be plus/minus for
 chemotherapy then chemotherapy and radiation.
- O0:12:31 So all of this makes a lot of difference of how you're going to treat patients because your diagnosis or the staging has to be accurate.
- O0:12:41 And so when a patient has a Stage IIIB, then they cannot be -- their tumor cannot be removed anymore, and so they are usually -- the standard of care in those patients is radiation and chemotherapy.

- O0:12:59

 And once patient develops metastatic disease or the cancer has spread to other parts of the body, then the only treatment will be other chemotherapy. I should also mention that there should be also targeted therapy that we now have for lung cancer. Next.
- O0:13:16 So this is a grouping of TNM staging. So I think this is an animated slide, so you can keep on -- you can keep on going on this slide and I can explain once this all comes -- Okay. Thank you.
- O0:13:33 So the lung staging is done by T, N and M. T is the size of the tumor. N is the lymph nodes involved and M is if it has spread to any other part of the disease.
- O0:13:46

 So, as you see, that is there are no lymph nodes involved, it becomes TI, and the size of the tumor, and if there are -- are -- the sizes of the tumor decides what is the T, and is -- whether lymph nodes are involved or not.

- O0:14:05 So from -- [go ahead] -- So from Stage IA to IB, the difference is only the size of the tumor. So IA is described as a tumor that is less than four centimeters, and if a tumor is more than four centimeters it is IB.
- Now, what I did not mention in the other slide is that that makes a big difference as well in the treatment, because just to get my point is that from IA to IB, if the patient, once they are (inaudible), now, the [center] of care is adjuvant chemotherapy.
- O0:14:42 And the patients who [have] adjuvant chemotherapy, the studies have shown, that it is -- actually doesn't help in Stage IA patients, could be detrimental, but there is some data that IB patients could benefit from that. So even the size of the tumor is important.
- O0:14:59

 And then as we go further, then, it depends on the lymph nodes, so if lymph nodes are involved locally, it makes it Stage IIA, and once the lymph nodes go in the upper part of the bronchus, which is around the mediastinum there, it becomes IIIA, and if it goes to the other side, it becomes IIIB.

- O0:15:22 And, again, then, if it goes to other part, for example, the brain here, then it becomes Stage IV.

 Next.
- O0:15:32 So how do we evaluate these patients? How do we find the staging? So we start with a physical examination, chest X-rays, but, then, finally, we have to do CAT scan, because they are very helpful in finding what is the size of the tumor, what parts are involved.
- O0:15:53

 And, nowadays, you know, [PET] scans have become very much part of the workup which -- it has 20 percent of the time what the CAT scans have not picked if the cancer has not gone other points of -- other parts of the body, [PET] scan will help us with that. So it has become a very important (inaudible) to when we are making decisions whether this patient should have [resection] or not, [PET] can be very helpful to help us with that decision.
- O0:16:26 So if we suspect there is a mediastinal involvement, then the way to biopsy it -- So we never -- You know, lymph nodes can be enlarged without having cancer in

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them. So even if the lymph nodes is enlarged, we always do a biopsy to prove that it is cancer, because we are changing patient's treatment based on it.

- 00:16:50 So we do have to -- and the patients do,
 unfortunately, have to undergo invasive studies,
 sometimes or most of the time, which could include
 bronchial -- trans-bronchial biopsies, (inaudible).
- Now, if mediastinum looks totally normal on the CAT scan and the PET scan, then the patient can [just be taken to] surgery, and, again, the surgery is a surgical etiological specimen, we'll, at that point, finally decide how the patient should be treated.

 Next.
- 00:17:30 Well, so it is a very -- As we know, it is a very -- and the patients know -- it's a devastating diagnosis. When the patient comes to my office the first thing they are -- you end up doing is to try to explain to them that, you know, it is very important that we do all the tests, that it is very important how we treat these patients, depending on the staging.

- O0:18:01 And, you know, most of the times, patients will come and they will still, Well, if I have lung cancer, just treat me today. Why do I have to wait another week or two?
- O0:18:09 So I end up explaining to them that, you know, what we -- how we stage their treatment will depend on it and I cannot go back and treat them correctly if I have done the staging incorrectly.
- 00:18:24 So it is a lot of explanations that a doctor has to do in the beginning when the patient is diagnosed with the lung cancer.
- O0:18:37 They are undergoing testing, so it's a lot of family support and friend support that they need to go back and forth for tests, for scans. And it really changes a patient's life. You know, they are living a normal life, like all of us, and, all of a sudden, their whole life changes. So it does make -- You know, it is a big impact on their social (inaudible), family and all family dynamics.

- O0:19:12 Most of the people have not thought of, you know, that, you know, this can happen to them. We don't think it, but, then, when it does happen, so they have to make a lot of decisions quickly on many things that we think we can do tomorrow. Next.
- O0:19:31 You know, we kind of -- As physicians and treating patients with cancer, we learn how to shield our emotions a little bit, but it's still very hard for a physician every time they go to the patients and the families to break the bad news that, you know, they do have cancer, especially lung cancer.
- O0:20:00 Then, the second thing that becomes challenging is to scheduling and (inaudible) about how to (inaudible).

 So you can't -- Most of the time, you know, you have to coordinate with the scanners, you have to coordinate with scan people, PET scan people.
- O0:20:19 And then you have to go, and many times, I can't tell you that. You know, when you go to the scan people and they have made some kind of diagnosis, and when you give them the patient's history, they will change it.

- O0:20:30 So it is important that, at that time, the physician gets involved with all aspects of that patient's scans and the coordinating of their care, so if a patient needs a bronchoscopy it has to be coordinated to get a pulmonologist or the (inaudible) who can do ultrasound guided by (inaudible).
- 00:20:51 So all that needs to be coordinated by this physician, although the physician [extenders] or nurse practitioners or the nurses are (inaudible) help at this time. Next.
- O0:21:07 So when the treatment comes, I think that is much more challenging from the patient's point of view. So I sometimes, myself, say, Okay. You know, if I'm telling my patient, Do this, why would the patient want to listen to me? So, you know, this depends on how confident the patient feels about yourself.
- 00:21:33 What I always tell my patients is this is what I think we should do, but I encourage them to get second opinion. And I am surprised, most of the time -- and, actually, the patients are surprised most of the time

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when I suggest that, because they always think that maybe I should have a second opinion, but then they will -- You know, they feel like they shouldn't discuss it with me because maybe I'll get offended.

- O0:21:58

 So I always explain to them that it is not that you don't have confidence in me, but you will be more confident, you know, in me if you do get second opinion, and if it does differ, we can discuss this
- O0:22:15 So the patient becomes very comfortable with this discussion, and they, most of the time, will be very happy. And I actually would call, you know, wherever their choice is to my colleagues and get them a second opinion, so that they feel comfortable with the decision as well.

and we can discuss pros and cons of this.

O0:22:40 Is there a difference between a large academic center and community? And, you know, a lot of patients will ask that question, and if there is -- what the differences are.

- O0:22:54 So what I also talk to the patients is that when they are initially being diagnosed, and if there are small community hospitals and community hospitals do a wonderful job and their physicians are wonderful and they are equally qualified as a large academic site, but it's just that sometimes the large academic sites can coordinate care very carefully.
- O0:23:22 For example, I worked in Georgetown, so -- or, now, I work at the NCI Clinical Center, so we had like multidisciplinary clinics where patients would come.

 We, as a group, would see patients as a medical oncologist, radiation oncologist. We'll have surgeon in the room, and we will have a radiologist in the room.
- 00:23:43 We will look at the patient's scans together, talk to the patient together and within a day patient will have a plan of care.
- 00:23:51 Now, that is a little bit harder in the community center when -- community areas where patient will have to go one by one to each physician and then make a decision, so it helps in that.

- O0:24:04 And the second thing it helps is that if there are any clinical trials that are not open in the community that, hopefully, most of the large academic centers will have.
- 00:24:17 So that those are the two main reasons why patients could -- I explain to my patients -- should consider coming to the large academic center.
- Dut once a treatment plan is made and a decision has been made and -- whether the patient can be treated with community, where it is easier for them to commute than to come to -- You know, sometimes, they have to come hundreds of miles and that's just not -- that's too much burden for the patient. So I encourage them to get treatment locally once a plan has been made.

 Next.
- O0:24:54 And the second question is whether the patient has challenges whether they should participate in a clinical trial or not or should they get standard of care. It really depends on how much patient knows,

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and we, as physicians, educate them what clinical trials are.

00:25:26

Sometimes, a patient will [write], come and say, Well, I don't want to be a guinea pig, so I don't want to, you know, go on a clinical trial or sometimes the patients -- other patient will come and they will come actually [list off] the internet -- The patients have access to all the clinical trials that are going on, so they will come up with the list of trials that they could participate in. In fact, on a larger list than, you know, they could participate in and ask you, Well, why can't I go on this trial or that trial?

00:25:49

So it really depends on individual patient. So -- And it depends on what the trials will be available, how easy it will be to have patient access them. So that is one of the other discussions that goes on with the patients and are challenges for the patient to decide that they want to participate in clinical trial or not.

- O0:26:14 Second point is what will happen to me? How long will I live? These are the questions you always get, and, unfortunately, I tell my patients I don't know.
- O0:26:26 What will happen, I do tell them that they could get, you know, short of breath, and, you know, they could have pain, but, you know, you do comfort, and, at the same time, that you are there for them, and if they do develop any kind of pain or symptoms, you're there to support them and make every effort that they will be taken care of.
- O0:26:50

 You know, when they ask you how long they will live,
 you give them the real picture that, in your stage of
 cancer, this is what, you know, what normally people how long they live.
- You be honest with them, but, at the same time, you know, you know, you have to be empathetic. You have to be explaining to them that, you know, each patient is different and that it also depends on how well you take the treatment, and that if there are any things out there that might change some of their, you know, (inaudible) their disease.

- O0:27:36 And the pain is always an issue that patients always think that will they die in pain, and, you know, we now have hospice care. We have palliative care, and so I make patient, depending on their, you know, this pain and all this discussion is mostly with advanced stages (inaudible), and we talk to them.
- 00:27:58 We involve all the palliative care people, and they're really, really helpful to us to help take care of the patient and explain to them. They talk to them a lot and help them, you know -- help them education about the pain and how we will be able to control it if and when it happens. Next.
- O0:28:26 So, again, making decision about the therapy, you do the best you think you -- the patient will benefit from, so you will spend a lot of time thinking about what will make it best.
- O0:28:38

 Again, you have to give patient the realistic picture of prognosis, but not to take hope from them at the same time. It can be, sometimes -- You don't want to give patient too good -- It sometimes has happened

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that, you know, patients are given information, Oh, yeah, you know, we can take -- You know, we'll cure you. We'll work with you. We will beat this together. That's a false hope.

- On the other hand, there are sometimes the patients are said, Oh, well, you have Stage IV lung cancer.

 You're not going to live more than three months.
- O0:29:14 So you can see patients given advice or, you know, spoken to with -- differently by different people. So you have to have a good balance of giving them realistic picture.
- O0:29:32 But, again, really we don't know how long each patient [even lives with this], you know. And stage disease or Stage IV disease, sometimes I've been surprised myself that a patient I thought was not going to live or have prognosis of six months will live for a couple of years, too. It really depends on the patient.
- O0:29:55 So finding the best clinical trial is a challenge.

 Again, if you are seeing a lot of patients, you have to take time out and really find good clinical trials

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that will benefit the patient and help them thought through what they will be eligible for and what will make sense for their stage of (inaudible). Next.

- 00:30:23 So I just would -- couple of case studies where it did make a difference for the patient what they -- about when they made a decision in one way or the other.
- O0:30:36

 So I had a patient -- these are real patients -- and without name. So I had a patient actually [who has] -- a few years ago, a 70-year-old gentleman who was diagnosed from a community hospital. I think it was somewhere near Virginia Beach with lung cancer.
- O0:30:56 The physician had told him that he has lung cancer, and he could get chemotherapy or since he is 70 years old, he could just live about six months, by his estimate, and not get anything.
- 00:31:11 So his son actually worked in D.C. and so he brought him to Georgetown for a second opinion, and I -- and brought him to my clinic.

- 00:31:25 So we actually did a workup on this patient. He was 70 years old, but he was from Army and he was in a perfectly good shape.
- O0:31:34 So we brought him to our multidisciplinary group and the surgeon saw him on the same day. We did all scans, PET scans and CAT scans, the same day.
- O0:31:46

 And we -- our evaluation showed that this patient had actually only Stage IIB disease. So he breezed through the surgery. He was actually -- In one month, he -- that I saw him -- he looked perfectly, you know, in good shape in performance standards of zero to one, where he was, most of the time, out of the bed.
- O0:32:18 And we were actually able to give him actual chemotherapy also for four [cycles] and he is still in touch with me. He is (inaudible) six years later.
- 00:32:28

 Now, this [position] changed his whole outlook,
 because he decided to get a second opinion. So he
 could have not gotten any of these aggressive
 therapies and he could have -- and his cancer could

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have grown further and may not have lived as long. Next.

- O0:32:56

 So another patient I saw a couple of years ago who I very close to my heart, was a 45-year-old lady, very
 young woman, who was an ICU nurse by profession. She
 came to the ER.
- O0:33:13 She was -- Apparently, she had made an appointment to see me, but ended up in the emergency room because she developed shortness of breath acutely.
- 00:33:24 So she had -- On (inaudible), what we found was that she had a large pleural effusion in lung, and so we drained it and she metastatic lung disease.
- O0:33:39 At that time, she took one cycle of chemotherapy. She was still in the hospital. She actually worsened. So everybody started saying, you know, she's just doing bad. We put (inaudible) oxygen mask on her, and the plan was that she was going to go on hospice.
- 00:33:59 And so while she, you know, was there, she actually started a targeted oral agent. At that time -- it was

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a few years ago -- it was not approved (inaudible), and we also did not have the way -- we were not checking as a routine the (inaudible) mutation. So she said, Well, I have nothing to lose. It's an oral therapy. Let me just go ahead and start it. Next.

- O0:34:35 So two weeks later, she comes to my office. Her oxygen requirement has gone down. She was only on two liter. There is one before this? Can we go back to the slide?
- 00:34:55 AMOLA SURYA: Yes. Sorry. We are doing that --
- 00:34:58 DR. SHAKUN MALIK: Okay. No problem. No problem.
- 00:35:01 AMOLA SURYA: Here we go. Can you see?
- O0:35:03 DR. SHAKUN MALIK: Thank you. Yes, I can. So she improved. Her oxygen slowly got down, and she actually got off of oxygen in six weeks.
- O0:35:11 And, you know, about -- You know, she sent me a thank you card around Thanksgiving, which I still keep with me, because that was a very nice card I got from her

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telling me that, you know, that I had made her able to spend Thanksgiving with her family, which I had nothing to do with it.

- O0:35:31 But she lived for 15 months, and she eventually was resistant to this drug as well, and she passed away, but she lived about 15 months. And so her decision of going on experimental therapy at that time changed the outlook for this patient, in my opinion.
- 00:35:52 Okay. I think that was the last slide of my presentation. So I wanted to keep about 20 minutes for questions and answers.
- 00:36:02 AMOLA SURYA: Thank you, Dr. Malik. At this time, I will now turn the call over to Dr. Jerry Suls, senior scientist at the Behavior Research Program.
- 00:36:12 As a reminder, this webinar is being recorded. All lines will now be unmuted.
- O0:36:21 DR. JERRY SULS: Thank you, Dr. Malik for a very interesting and informative presentation.

- 00:36:26 We have a number of people on the line, so I hope they're going to offer questions. I'll start with one.
- O0:36:35 You mentioned the fact that there's usually considerable distress and upset when the diagnosis is given, when they get a diagnosis of lung cancer.
- 00:36:48 What percentage of people, on average, once they hear that diagnosis, really just opt out of almost everything with regard to medical care? Is that a very small minority or is that a healthy percentage?
- DR. SHAKUN MALIK: No, it's a very, very, very small minority. If I recall from my practice I would say I have had one patient who said that, but then came back and got treatment.
- DR. JERRY SULS: Okay. A second question I have which is connected to the family dynamic and the patient and the decision for treatment, I'm wondering whether there's a -- Tell me whether there's a difference with regard to lung cancer patients who are smokers as opposed to those who are not smokers and, therefore,

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may be subject to lung cancer because of asbestos exposure or radon or some other environmental toxin.

- O0:38:03 And I wonder is the family dynamic going along with the decisions that have to be made about trials, trial participation and treatment, et cetera, whether those things -- whether that looks like that's different or whether they really look about the same.
- O0:38:21 DR. SHAKUN MALIK: They, in general, look about the same. However, I feel that, you know, the patients who are non-smokers, they are actually more angry because -- and their family, but mostly the -- you know, especially the patients.
- O0:38:40 I mean, I had a young woman who was diagnosed with bilateral lung cancer and her daughters -- and she never smoked. Her daughters were very angry.
- O0:38:49 The anger is that I -- You know, this happens to smokers. I never smoked. Why me? So they are really angry about it. So that is only one difference.

- O0:39:01 Other than that, you know, they equally will, you know, participate in the treatment (inaudible). The family will be there. They will support them, and there is not too much of a difference how they decide about their treatment.
- O0:39:21 DR. JERRY SULS: Okay. You didn't talk about the national lung screening trial, and I wondered if you might say something about that in this context.
- O0:39:36

 DR. SHAKUN MALIK: So, you know, we were participants in Georgetown for the National Lung Cancer Screening Trial as well. I didn't talk about it because that was a screening trial and we were talking about once the diagnosis is done, but I can talk about it.
- 00:39:54 So this was a screening trial where patients who had smoked and -- a pack -- had a 100-pack history and then they were more than 45.
- 00:40:06 And they were randomized to either getting a chest X-ray or a CAT scan, and a CAT scan was statistically significant that it [picks] the lung cancer earlier.

- 00:40:18 What was the problem with this is that, you know, you do pick up lung cancer earlier and a lot of people -
 I mean, a lot of like agencies or groups are endorsing it, but there is some controversy about it.
- O0:40:43

 The controversy is that most of these patients will find -- we will find -- there's a high percentage that we will find these small [nodes] or small masses in the lung, but, you know, they are -- when they are biopsied, they are benign. They are not cancerous. So there is a smaller percentage of cancer, but a larger percentage of patients who do not have cancer.
- 00:41:09 So then you are putting the patient to the test and so the [morbidity] associated with it is a bit controversial.
- O0:41:19

 And the other point of controversy is -- And we did see a number of patients in Georgetown where they will come with these small nodules, and so we made our own algorithm, but it has an algorithm now that if the nodule is this much you wait for this much and then do another scan and all that.

- 00:41:36 But you end up doing lots of scans, which may not have been done before, and you end up biopsying a lot of patients who do not have cancer.
- O0:41:48 So, you know, from the [federal] point of view or the public-service point of view it becomes also a question how much money we spend. So it's still an evolving discussion that's going on at the current time.
- O0:42:06 DR. JERRY SULS: Do you think that this is going to -Is this going to produce a lot of interest on the part
 of smokers to try to get the test even though there's
 still considerable controversy about it?
- O0:42:25 DR. SHAKUN MALIK: Yes. Absolutely. I mean, smokers are going to still get it, and what I heard last was that there were some smokers who would get it, and if it is normal -- So, again, there is, again, a controversy about that.
- O0:42:39 So the smoker goes and gets this CAT scan, so he says,
 Oh, my CAT scan is normal. Let me just continue
 smoking.

- O0:42:46 So it's kind of a, you know, negative impact for some of them, but, you know, I think that smokers will, just because of the -- that it is available, and some insurance companies do pay for it, they will go and get it.
- DR. JERRY SULS: You had mentioned something about there being initial exams and then scans done and that there was some inconsistency or -- I didn't quite follow that part of your presentation that there was something happening between the initial sort of testing and diagnosis and then scans and there being an inconsistency across medical units, and I wonder if you could clarify that --
- DR. SHAKUN MALIK: Oh, sure, sure. No, I mean -Right. So it's not inconsistency. It is a matter of,
 you know, being -- So if a patient has a CAT scan.
 and, you know, so there was lung cancer and somebody
 biopsied it and said, you know, lung cancer, and so
 then what I'm saying is that then you have these kinds
 of patients you have to be very aggressive with

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staging, so -- because staging makes a big difference in how you treat these patients.

- O0:44:07 Like I presented that one gentleman who was 70 years old. The patient's physician did a CAT scan and did a biopsy, which is very appropriate, and then said, Oh, you have lung cancer, and, now, you know, you can either take chemotherapy or nothing or maybe radiation therapy, if you want. So --
- O0:44:27

 But what happened was then he came to [bigger centers]. We actually went aggressively. We had him not only the CAT scan, we then (inaudible) a PET scan.

 We didn't find cancer anywhere.
- 00:44:38 We then went and did a mediastinal lymph node biopsy sample which didn't find any cancer there, and then we took him for surgery.
- O0:44:48

 So, sometimes, you know, you have to do more -- be more aggressive about staging to make these patients whether they are (inaudible) we are able to take the cancer out or not. So that is kind of -- In the beginning, it's very important to stage them.

- On the other hand, we could have a patient who we have done everything, but have not done a PET scan, and, then, you know, we -- and that patient undergoes a [resection] of the lung cancer, and, then, maybe, you know, two months later somebody -- he has a pain in the leg, we order the PET scan and he has a tumor then that, you know, we had patient have all the surgery done when he had cancer in the bone.
- O0:45:32 So there is not a consistency. All I'm saying is that

 -- I mean, inconsistency. All I'm saying is that in
 the beginning, one has to be very (inaudible)
 aggressive of staging these patients, that staging is
 very important.
- 00:45:48 DR. STEPHANIE LAND: This is Stephanie. If I could jump in with a question.
- 00:45:51 DR. SHAKUN MALIK: Yes, Stephanie.
- O0:45:53 DR. STEPHANIE LAND: Yes. Hello. Thank you so much, Shakun, for a really nice, interesting presentation and for being involved in the effort.

- O0:45:59

 I have a couple of questions, and they're both related to our mission as a decision-making steering committee.
- O0:46:06 And, Jerry, you'll have to correct me if I misstate, but I think, you know, part of our purpose is to help people who work in the science of decision making better understand the decisions that are being made by clinicians and patients.
- O0:46:23 And, then, there's a second piece, which is to feed back the research produced by decision scientists to the clinical community, to the clinical-care setting.
- O0:46:36 And so my first question relates to the first piece of helping decision scientists understand. My question for you is, and you have described a number of ways in which decisions are made in the process of lung-cancer diagnosis and treatment -- adjuvant therapy or not, second opinion or not, major medical center or community care, resection, experimental treatment, getting screening or not and so on.

- O0:47:04 And I wondered if you have found decision-making scenarios that are puzzling where you feel that it's not -- you know, that clinicians maybe need to know more about how to interact with a patient.
- O0:47:20 And, for example, you talked about, you know, the big team meeting with the patient. And I know there is some research on that kind of setting and sort of ways to approach the patient that will make them comfortable that they are, you know, making a -- you know, the right decision.
- O0:47:40 Are there settings or scenarios where you feel we need a decision scientist to do some research to address how clinicians can better work with patients or how patients can better function in making all of these decisions?
- 00:48:01 DR. SHAKUN MALIK: I think that the most important thing the physician needs to do is to really talk to the patients and -- after making the diagnosis to explain to them --

- O0:48:19 DR. STEPHANIE LAND: Can I -- Wait, can I cut in?

 Cause I don't think I asked my question very well.
- O0:48:23

 So I'm not asking what you think or how you think these things should be done in the clinical setting.

 What I'm asking is what do you not know about how to help in these decision-making moments? What do you not know that you need to know?
- 00:48:44 DR. SHAKUN MALIK: What do I not know that I need to know?
- O0:48:46 DR. STEPHANIE LAND: Um-hum. Um-hum. Do you have questions or concerns or things that puzzle you about how decisions are being made?
- O0:49:02 DR. SHAKUN MALIK: I would have to think this,

 Stephanie. So you are asking, you know, what do I

 think that the patient should -- how I can -- could

 have been helped? Is that what you're saying --
- DR. STEPHANIE LAND: Well, no -- Well, no, for -- For -- I mean, just to, I guess, give you an example.

 Have you been puzzled about that -- Say you feel that

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you've given the patient information that suggests that they should take a particular approach, but then they go back and talk to their family and they seem to take an approach that you would not have recommended.

- 00:49:40
- I mean, that -- I don't mean to focus in on that specific kind of scenario, but that would be one where you might say, Gosh, I don't really understand what this process is. Why are patients in this particular sequence of events making this kind of choice? That makes no sense to me.
- 00:50:00
- I wish that we could do research or an experiment to better understand why patients are going forward the way they are and how we can perhaps do things differently so that they will make a decision that's more consistent with, you know, the better outcomes.
- 00:50:20
- DR. SHAKUN MALIK: Yeah --
- 00:50:20
- DR. STEPHANIE LAND: Does that make sense?
- 00:50:21
- DR. SHAKUN MALIK: Yeah, yeah. I mean, I know what you're saying, but, I mean, each patient is

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(inaudible). So, in general, it is you are not sure, you know, if the patient made a decision why did they make that decision.

- 00:50:35
- You're not sure that if they chose not to go on clinical trial, then you have explained everything to them and you tell them that this is -- will be a good thing for you, and they will not -- you know, they will not come up front and say why they chose not to. You know, sometimes they will and sometimes they will not.
- 00:50:57
- You know, sometimes the patients will choose that, you know, offer meeting with you and making a decision with you on a treatment. All of a sudden, you know, they say, Oh, no. I don't want to get -- you know, be treated in this center. So these are the things that, you know, it's very highly individualized.
- 00:51:23
- So is there anything in particular that I would like to know? I think that most of the important thing that a physician would like to know is, you know, what makes patients decide that, you know, whether they want to go -- I think clinical trials may be one of

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the things what makes them think that -- what makes them decide to go on or not go on, because you give the same information to each patient, but, then, some patients decide to go on clinical trials, some don't.

- 00:51:55 So I think that if you're looking at, you know, something that should be looked at is to see, you know, what are the reasons why a patient would or would not go on a clinical trial --
- O0:52:10 DR. JERRY SULS: This is Jerry. I wanted to interrupt for a second and kind of ask it in a different way.

 I'm wondering whether, in your experience, whether -
 It seems to me that the patient who might pose the most problem or would have the greatest indecision -
 and the physician would as well -- would be the person who's at a IIIA stage.
- 00:52:31 DR. SHAKUN MALIK: Um-hum. Um-hum.
- 00:52:32 DR. JERRY SULS: Where the survival is, you know, it's probably about 10 to 30 percent.
- 00:52:38 DR. SHAKUN MALIK: Um-hum.

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the family to have to cope and try to make a decision.

- O0:52:38

 DR. JERRY SULS: Would that be consistent with your experience or anecdote that that would seem to be the most difficult meeting of the team? It would be -- seem like the most difficult place for the patient and
- DR. SHAKUN MALIK: Actually, you are right, and -But, however, you know, it is a more difficult
 situation for the physician than the patient, because
 if you tell patient at a Stage IIIA that, We think we
 can still resect your tumor, they are happy. They're,
 Oh, great. You can remove my tumor.
- Dut, as a physician, that is one of the hardest stages that -- where you have to make decision, because you have to check that, you know, there is data that if you remove their right-sided lung, they have a 50-percent chances of dying after, you know, you give them chemotherapy and radiation. Harder decision, actually, more harder, like you said, for doctors.

- 00:53:39 But for a patient, they actually think, Oh, well, if you think I can, you know, have it removed, then that is good.
- O0:53:48 And I'm even surprised like sometimes patient will have Stage IV lung cancer and they will say, Oh, why can't you remove it?
- O0:53:53

 DR. JERRY SULS: Um-hum. So, and when you say, you know, one of the uncertainties is, it's really the medical uncertainty you're talking about.
- 00:54:01 DR. SHAKUN MALIK: Correct.
- 00:54:01 DR. JERRY SULS: Whether the resection would be the appropriate thing to do.
- O0:54:04 DR. SHAKUN MALIK: Right. Right. You want to treat the patient, do the resection, but you don't want it to be, you know, you don't want all this -- You don't want patient to die. You know, you don't want to have it (inaudible) a mortality associated with it.

- O0:54:15 So we, as a group (inaudible), Okay. Can you check the patient (inaudible) preoperatively. We check their, you know, FEB1 (inaudible), that if we remove the part of the lung or the whole lung that the patient can still survive.
- 00:54:28 So this is actually -- You're right. It's one of the hardest stages that you have to make a decision on as a physician.
- O0:54:40 DR. BILL KLEIN: Dr. Malik, this is Bill Klein, and thanks again for the great presentation. I really appreciated the case studies.
- 00:54:44 I just had a quick question for you, and I know we only have a little time left, so I'll make it quick.
- 00:54:49

 I'm kind of interested in how much time patients actually spend making the decisions that you're talking about in these case studies.
- O0:54:55

 I imagine there's a great deal of variability.

 Sometimes they make it right there in the office.

 Other times, they may need to take a week and spend

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time talking to their family and do some research, but is there sort of a --

- 00:55:04
- DR. SHAKUN MALIK: So, you know, it's also -- like you said, it is variable, because some patients are like, Oh, I need to make a decision today, because if I have cancer I don't want it to be -- you know, I need it to be treated today. So --
- 00:55:15
- But some patients will say, Oh, no, I -- You know, I'm going to take my time. But to be -- You know, to -- In general, in general, most of the patients will make a decision. You know, if they want to have a second opinion, they will make a decision, you know, fairly quickly, because they know that they have -- a cancer that needs to be taken care of.
- 00:55:36
- So they don't take a long time, but, some people do try to make decisions quicker, but others may take a week or so, not more than a couple of weeks. I have not seen patients (inaudible), I'll let you know next month.

00:55:49	You had something different in your mind that you were asking me.
00:55:52	DR. STEPHANIE LAND: Well, that was helpful. I can also just talk to you off line, cause
00:55:56	DR. SHAKUN MALIK: Yeah, we could chat offline. Yeah
00:55:59	DR. STEPHANIE LAND: Yeah.
00:55:59	DR. SHAKUN MALIK: Okay.
00:56:00	DR. STEPHANIE LAND: [You know, a bigger meeting.] So, Jerry, I don't know if there's more time And others may have questions.
00:56:05	But, yeah, I'll be happy to follow up later. Thank you so much
00:56:10	DR. SHAKUN MALIK: Okay. Thank you, and if anyone has any more questions, you are more than welcome to email me and I'll be glad to

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00:56:15	FEMALE SPEAKER: everyone to read and download in a
	few weeks. So thank you so much for your
	participation.
00:56:21	DR. SHAKUN MALIK: Thank you. Bye.
00:56:23	MALE SPEAKER: Thank you very much, Dr. Malik.
00:56:24	DR. SHAKUN MALIK: Thank you, doctor. Thank you
	doctor. Bye-bye.

END OF TRANSCRIPT