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JULY 10TH, 2014

00:00:00 AMOLA SURYA: Good afternoon and thank you for participating in the Decision-Making Steering Committee Speaker Series. My name is Amola Surya and I will be moderating today's webinar. I would like to introduce this afternoon speaker, Dr. Steven Katz, Professor of Medicine and Health Management in Policy at the University of Michigan.

00:00:20 Dr. Katz will discuss his personal experience as a Practitioner and what he identifies has the most challenging issues in cancer prevention and treatment. 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 someone will have you. I will now turn the call over to Dr. Katz.

00:00:47 DR. STEVEN KATZ: Well, thank you very much. It is a real pleasure and a privilege to be able to lead a discussion on this important topic with my colleagues at NCI. I have been continuously funded at NCI since about near 2000 and I think that we've done some really great research here at Michigan, but what I

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think that people don't quite realize is that when you have this kind of funding relationship with NCI, you also learn a lot from colleague.

00:01:15 I've had incredible opportunities to share with colleagues both in Washington, frequent fore's to NCI and having some colleagues come here on a regular basis at the University of Michigan. This would include people like [inaud.], Steve [inaud.] who has recently left NCI to join [inaud.], Rachael [inaud.] had some delightful conversations with Bob [inaud.]. I'm very much informing my research and so I look forward to today to this kind of discussion.

00:01:47 So, the topic is Decision Making Steering Committee Speaker Series. I am Steven Katz. I'm a Professor of Health Management and Policies at the University of Michigan. Next slide please. The charts for the webinar that I was given was to help lead a discussion regarding the most challenging issues in cancer prevention treatment and/or survival that may involve decision making by practitioners, patients and/or caregivers.

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00:02:15 The choice of my topic today is on treatment of breast cancer because that is I've studied prominently as a Research Scientist. My brief comments today are really informed by my research but I'm also a practicing Internist not in cancer. But I spent a limited amount of time Fridays, in the privileged position of taking care of Veterans in our Emergency Room at the University of Michigan's VA.

00:02:41 So the issue of decision making and communication resonates with me as a research topic but also is a Friday dialog as I work with residents, patients, in the emergency room at the VA. I also say that as we grow older we have experiences of our family and our friends and our own patient experiences that very much reflect or inform the kind of discussion that we'll have today. So, next slide please.

00:03:07 So, I've chosen to discuss briefly some of the challenges in regard to individualizing treatments for breast cancer. Next slide and my agenda is brief. In the next 15 minutes describe the clinical treatment context for our discussion. Explore challenges to communication and decision making in that context.

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And then I'm going to elucidate a research agenda going forward that very much is reflective about the program here at the University of Michigan that I lead. Next slide.

00:03:41 As a general Internist, I have really been excited about the opportunity to evaluate communication decision making in the breast cancer treatment context. I actually feel that breast cancer context is way out in front with how precision medicine will translate to better individualizing of treatments in the clinical encounter. And as a general Internist, they're probably no other tracer condition as far forward in this area as breast cancer, incident episodic disease.

00:04:16 Virtually, the treatments that confer lifetime benefits are initiated and largely completely in the first year of diagnosis. Most decisions are made in the first weeks of diagnosis. Patient receive multi-modal therapies directed by different specialties that they are meeting for the very first time. Mature evidence based on management's and treatments and cancer treatment is widely disbursed in the community.

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00:04:39 What I mean by that is that it is the bread and butter condition for 95 percent of breast - of medical oncologist and there are literally many thousands of surgeons who are involved in treatments nationwide. Next slide.

00:04:56 And another major point that is not new to any of my colleagues on the phone today is that the wide shift in, or the large shift in more favorable prognosis patients diagnosed today based on 20 years of screening. The kind of change in the epidemiology that we've seen in colorectal cancer, more recently, prostate cancer and breast cancer that to some degree changes what the encounter is about with regard to communication and treatment decision making. Next slide.

00:05:29 And so, the challenges in patients with favorable prognosis which is a dominate case presentation or patient presentation in the United States is that the net benefit of treatment options is often small and difficult to formulate for individual patients. Management and treatment options are morbid and

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burdensome. There's probably no more morbid and burdensome treatments in the medicine box than the kinds of options and therapies that patients are exposed to in cancer.

00:05:59 There's increasing recognition of patient harm, the treatment is too aggressive and [inaud.] is increasingly on the agenda for clinicians first do no harm. The studies are on their way to evaluate strategy to avoid morbidity and burden on patients and of course we need to understand communication decision making in the exam room if those advances are to translate into improvements in human health. Next slide.

00:06:25 So, as we know on the phone, there are many advances or initiatives going forward to consider less burdensome and more morbid surgery. Less is better than more, whether it's looking at [inaud.] lymph node dissection today, the role of lumpectomy versus mastectomy, the role of evaluating margins of therapy to reduce the probability or the possibility of re-excision after lumpectomy.

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- 00:06:57 Bigger surgery, not necessarily better and a lot of the initiatives to evaluate how to bring that forward to reduce morbidity in patients receiving treatments. Radiation omits less than partial breast radiation versus more. A lot of important trials going forward to evaluate those opportunities and options for less burdensome and morbid therapy.
- 00:07:21 And of course, the chemotherapy decisions to do or not to do were evaluating more precision in the testing to allow us to [inaud.] benefit and to avoid chemotherapy in patients who would not benefit by it. Lead by physicians, surgeons and medical oncologists over the last 30 years. Next slide.
- 00:07:43 And of course in the breast cancer the big shift towards tumor biology trumping antinomy with regard to now today three tests, three tumor biology tests, ER, [inaud.], 21 gene [inaud.], largely directing chemotherapy in patients with anatomy remaining an important element but increasing have become more dominant in terms of decision making.

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00:08:13 We see a large rise in genetic testing probably over the last year with the myriad decision that puts in place the role of genetic testing in the initial treatment decisions of patients newly diagnosed with breast cancer. That is a very new development, probably shifting by the month. Next slide.

00:08:34 So, when I use the word individualized treatment I use it very differently than the issue of precision medicine or personalized medicine. Here in our program at the University of Michigan we've defined that along three-dimensional. Individualized care is achieved when the right value of tests are ordered and the results are interpreted the right way.

00:08:55 Treatment decision determine by evidence based clinical indications that address expected best benefit. But a third level is the decision quality, that the decision quality is high. The patient is adequately informed, satisfied with the process and their preferences are incorporated into the decisions. The right test, the right treatment but also the right communication in decision making. Next slide.

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00:09:22 So, there is an incredible need to focus on the clinical encounter in cancer. In the context of Breast cancer, two pairs of women report that all treatment decision are made by the end of the first encounter. Many times it's a first encounter with the surgeon and that includes their systemic therapy decisions.

00:09:41 That encounter is intense, meeting doctors for the first time and immediate appraisal report trust and infinity is established or not established. The communication process is rather unstructured as a clinician, as a patient, as a researcher. It is crystal clear that having communication on referrals in the exam room over 45 minutes is highly unstructured and highly variable.

00:10:05 There is a complex array of interconnected treatment options that must be addressed. Of course, increasing complex value of information, influencing the outcomes of these encounters is very challenging. In fact, I would argue it is relatively much easier to study the variability in communication and the potential outcomes, then influencing them and here at the

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University of Michigan, we have a program attempting to do both. Next slide.

00:10:33 So just to focus the next couple of minutes, the additional minutes I have focusing on a patient. This is Ms. Landry [ph.], a typical patient with more favorable prognosis, 68 year old principal, abnormal mammogram, core biopsy yielded invasive breast cancer, low grade tumor, ER positive, HER-2 negative, relatively small tumor, 2 centimeters and sentinel signal node negative, node negative disease.

00:11:01 This represents about half of women, diagnosed with invasive disease in the United States today. So, it's a very common presentation. Next slide. First of all, let's celebrate the advancements in treatment. This is a slide that I've used fairly frequently for clinicians and patients not that's it treatment in favorable prognosis scenario; no patient goes untreated unlike prostate cancer where we have the concept of active surveillance. The - we do not have that concept year extending in breast cancer.

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00:11:40 This patient has its favorable prognosis but really it's favorable after therapy. So, without treatment, this patient has a 40 percent chance of distant spread or death, at 10 years. Death from other causes, 10 percent at 10 years. Local regional therapy, whether it's breast conserving surgery with radiation or mastectomy have that risk. That is a real advance of course in medical care.

00:12:10 Hormonal therapy in this patient reduces that risk of distant spread or death by an additional 40 percent. Adjuvant chemotherapy by additional three percent and then the question of contralateral prophylactic mastectomy, which is not a question in most patients with breast cancer, is a little tiny tick on my figure just to honor the fact that there is a small proportion of patients who could benefit in terms of distant spread or death in 10 years.

00:12:44 But most patients who undergo CPM today are not in that category. Next slide. Now, with all of that a great advances comes the challenges of the complexity of the information that patients undergo. This is just one ICCN figure that shows the partsing out of

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chemotherapy decisions by a function of histology, the test results that ERPR and that gets into another category with regard to chemotherapy decision making. Next slide.

00:13:24 Which takes into account, tumor size and possibility the 21 gene [inaud.] yes, no? Now, of course, if you have never seen this before this looks awfully confusing, imagine being the patients. Just underscoring how complex the data today is informing chemotherapy decisions in these kinds of patients with favorable prognosis. Next slide.

00:13:47 And of course, how the tests unfurls over time in relation to the treatment decision is nontrivial and highly variable from the initial diagnosis confirmed biopsy which yields tumor behavior HER-2 to the history and physical exam and imaging directed by the first surgeon's visits which yields estimated tumor size, clinical notes, co-morbidity, to initial local regional therapy decision, surgery is done the yielding pathologic notes, margin status, 21 gene [inaud.] results to the final surgical decision that are based on the initial surgical outcome and finally

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systemic treatment decisions. Extensive disease, tumor biology, post factors, unfurling variably over time for each patient. Next slide.

00:14:39 And finally, one other element of complexity here who's at the table with Ms. Landry when she's making these decisions. Always the surgeon, the surgeon is the Primary Care Doctor with patients diagnosed with breast cancer. The medical oncologist, variably and whether that doctor is at the table at time zero in terms in decision making or later is highly variable.

00:15:00 Whether the radiation oncologist plays any role in the treatment decision making and of course whether there's a plastic surgeon involved with initial or even subsequent treatment decisions regarding reconstruction. And of course, other providers as a Primary Care Doctor I won't leave the Primary Care Doctor out but there is pretty compelling evidence that the Primary Care Doctor is largely cut out of these decisions. Next slide.

00:15:26 So, then I just want to summarize a research agenda that we're moving forward with here at Michigan with

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colleagues across the country and with funding from NCI the Psychology and Sociology, the treatment decision making how well is management of breast cancer individualized across those three domains. Testing, treatment, quality of decisions.

00:15:48 How are decisions made regarding test and treatments? How are patient preferences constructed? What is the role played by informal decisions to support people? A spouse, a sister, a mother, a friend. What factors influence clinician's attitudes and recommendations for tests and treatments? What is the role of their professional network? What is the influence of the professional network on individual clinician attitudes that very much influence how that clinical encounter is going to go? Next slide.

00:16:25 Then we are charged not only with studying how these decisions are made but implementing a research agenda to improve decision making. Or deliberation tools effective in proving to the individualizing of the management of care in the context of the chaos of that encounter, how do tools, online tools, however they are delivered that give patients information

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encouraging them to engage their doctors, how, when and where are those tools in this relatively time that patients take to make their decision?

00:17:03 What content and design is most effective in these tools? How do we integrate these tools into clinical workflow? How do we leverage advances in the electronic medical record to most efficiently and effectively deploy decision support? Next slide.

00:17:19 Now, what I just laid out in the last two slides is really almost ten years of research going forward but it is a kind of questions that are very exciting to me that is - that I have been charged to address both as a research scientist. My physician that informs these questions and of course all of us navigating our lives as patients, very much know and see what it is like on the other side of the exam table. With that I will conclude my brief comments and happy to have a discussion.

00:17:54 AMOLA SURYA: Thank you, Dr. Katz. At this time, I will turn the poll over to Dr. Jerry Suls, Senior Scientist with the Behavioral Research Program. As a

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reminder, this webinar is being recorded. All lines will be now be unmuted.

00:18:10 DR. JERRY SULS: Well, thank you for a very interesting and stimulating talk, Dr. Katz. I'm going to very soon ask for questions and discussion from others on the call but I want to start with a question. Which starts with actually one of the first things that you said, and you said that, you thought that, two-thirds of patients report that the treatment decisions, some of the initial ones and also some of the things that happen downstream are very frequently reported to be decided by the first encounter.

00:18:50 And I guess, my question would be really number one whether the patient feel that they are making those decisions and also do physicians on the other side of the desk actually think that those decisions have all been made during the first encounter?

00:19:12 DR. STEVEN KATZ: That's a great question. We've now studied waves of patients. The first large wave of patients that we studied was in the Detroit Metropolitan area Los Angeles County in 2000. Then a

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repeat in new cohort population based in collaboration with our [inaud.] registered colleagues in Detroit and Los Angeles in 2006-2007. And now, I have the benefit of a thousand patient's preliminary data of a new data set and a new population of patients that we have studied to date. So, it's been ten years of waves.

00:19:48 And I have to tell you in all three waves, and this now is going to be 5,000 patients and we are adding another 4,000 to the current wave. So, at the end of the 10,000 patients I'm hearing from women with breast cancer that at time of diagnosis - when they're diagnosed they're starting to think about their disease and many women are diagnosed before they hit their surgeon.

00:20:13 In the environment today in the United States, and probably the case in Europe increasingly invasive radiologists are doing the biopsies and if any of us on the phone have had abnormal testing moment as an imaging procedure or other, you know that the person who's doing this is not keeping their heart too close to their chest. You can even tell by their eyeballs.

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00:20:35 In the context of breast cancer, many women are diagnosed, told about their diagnosis by invasive radiologists and they walk into the room with the surgeon already talking to their friends, their family, online, etcetera. So, that decision making is in play in many cases before the patient walks through the door, and surgeons talk about that frequently.

00:20:58 So, they're already primed and then they walk in and patients report, this large cohort of patients, wave after wave that some of them made their decision about surgery even before they even walk in with the surgeon like 15 percent. And about half report that at the end of that one visit, they've made that decision.

00:21:18 The surgeons do - we've also done survey research of the surgeons and those surgeons do report a pretty pressured decision environment. It's moving really quick and they're often asked to sort of make close on this within the first encounter. So, one of things that we're interested in is slowing that process down because if it goes this fast, it is really hard to impact it or to change that if it's going this quickly.

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00:21:55 DR. JERRY SULS: Okay.

00:21:59 DR. STEVEN KATZ: There's certainly going to be a disconnect between patients and doctors regarding what they get out of the encounter, you know. But I would say that what we've found is that there is a bit of congruency regarding the speed in which these decisions are made and the reflection of the surgeon's and medical oncologist with regard to how fast they are made. There seems to be congruency on both sides of the exam table with regard to that.

00:22:24 STEPHANIE LAND: This is Stephanie Land. I have a couple of follow-up questions. One, you just mentioned the speed to which decisions are made and I wonder whether there's been evaluation of the need for speed. And the speed in itself may be of value in terms of reducing the stress of the decision making and the research shows cancer diagnosis overall to get to that point and feeling that this decision has been made.

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00:22:52 Then I had a question before that came up that I will just ask now as well which is whether it's your sense that aspects of how decisions are being made now are resulting in suboptimal treatment decisions? So, I am going to leave you with those two questions.

00:23:13 DR. STEVEN KATZ: Yeah, and those are great questions. Let's start with suboptimal first, you know, let's start with the outcomes and if we come back to individualizing the outcomes are that we would - we as a professional community would say that patients - the right patients are getting the right tests and the results are being explained the right way. I was getting a lot of echoing. Are people still on the phone with me? Are we still live?

00:23:46 DR. JERRY SULS: I think we're good.

00:23:48 STEPHANIE LAND: We're good.

00:23:49 DR. STEVEN KATZ: Sorry about that.

00:23:50 AMOLA SURYA: Yes, we are good.

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00:23:51 DR. STEVEN KATZ: So, the second issue is that the treatment followed guidelines, guideline concordance. That doesn't solve all of our problems but if we see a lot of discordance I think clinicians, would be troubled. The right test, the right results explained the right way. The right way treatment with - then of course the right decision quality that means the patients are satisfied, the patients are informed and the preferences are incorporated into the decisions and those are three big gulps to swallow in terms of what's going on.

00:24:25 I will say that patients do - you know there is a feeling affect in Breast cancer that patients - the satisfaction levels are quite high. However, the knowledge is quite low, how about that? The satisfaction is quite high, but knowledge is quite low and we know less about how to incorporate preferences into decision making.

00:24:46 That is a real wild west of measurements, of communication research. But it is a little paradoxical that we have observed over and over again

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high satisfaction, low knowledge. That's interesting,
what does -

00:25:03 STEPHANIE LAND: I know.

00:25:05 DR. STEVEN KATZ: - that say about the outcome. What
does that say about the outcome? Is there something
wrong with that? High satisfaction, low knowledge
it's really an interesting, developing observation.

00:25:16 STEPHANIE LAND: That may - this is Stephanie again.
That may just be a function of the confident in the
physician or it may be a preference of the patient to
have low knowledge. I am saying this partly as a
former patient myself, I think having enough to get to
the point of feeling confident in a decision is
perhaps the right amount and beyond that may be too
much. But I'm not sure quite follow whether - you
said yes or no, in terms of whether you think that
current decision making practices in the treatment
settings that you described are resulting in
suboptimal treatment decisions?

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00:25:57 DR. STEVEN KATZ: I think the answer is that for any medical condition that there's room for improvement. In breast cancer, I think we have a lot of opportunities for improvement because of the precision of the testing that we are deploying that can direct the clinician's recommendations regarding the benefit of therapy and the potential for futility with regard to more morbid therapy.

00:26:24 So, again one thing that I wanted to emphasize is that I think in this country over the last ten years, the sheer decision making mantra, that decisions are shared is probably not the most compelling framework for thinking about these issues that they have to be sure. Many women are voicing and we've studied this and we see it, that many women are voicing a strong navigator role that they wanted - a third of women in our preliminary data report that they - when we asked them whether they wanted to make those decisions or whether they wanted to be told what to do in a good scale, a third of the women said that they wanted to be told what to do all the time.

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00:27:15 That they had a very strong sense of reliance on the doctor to make the recommendation. So, it really reinforces the notation that part of a good decision is that the doctor knows what they're doing. I think there's some areas where we're doing well. I would say chemotherapy with 21 gene [inaud.] and the [inaud.] Trial, which will probably determine what's the [inaud.] for fertility in a large proportionate of women with invasive breast cancer that will be probably one of the most advance - best advances that we've made in precision medicine in healthcare.

00:27:51 Not just in cancer but other conditions. However, the rise of genetic testing over the last year and the rise of contralateral prophylactic mastectomy, which appears to be really on the rise, is food for thought about how we get the treatments right and we get the test right.

00:28:11 So, I think there's a lot of opportunities in breast cancer. One important issue is if we come from the framework of that the decision need to be shared I think that I this paradox between knowledge and satisfaction is misunderstood because I believe there

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are many patients in the world that are not seeking all the knowledge, what they're seeking is a doctor who they can trust to help them direct and navigate these very challenging decisions.

00:28:40 STEPHANIE LAND: Yes, I agree. I don't know if you wanted to say more about the speed of the decision and that in itself being perhaps an objective?

00:28:50 DR. STEVEN KATZ: I'm a little worried about the speed. I feel that the - there's a strong growing pressure really coming I think from patients more than doctors to get it done with and to move forward. We have written a couple of commentaries around the need for peace of mind and to leave things behind and with that - there's a strong, as many of you on the phone know, compelling psychology literature that really stresses the notation that when decisions are tough, you are in the intuitive mood.

00:29:24 You're in that think fast, think slow, you're in the think fast mode of what actually Jonathan [inaud] characterized as the elephant in us versus the writer, which is our cognition, our cerebral function I'm not

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on top of the elephant, the elephant is our initiation that sort of dominates our more primitive responses to decision making.

00:29:48 I think that intuitive process is deeply ingrained, deeply adaptive and really triggered when there is a diagnosis that's a threat and that all - that intuitive process favors fleeing the threat. You know, fleeing the fire and I think that really does move decision making very quickly. That from satisfaction perspective of patients is positive but I think with regard to contralateral prophylactic mastectomy, which is getting rid of the organ that is potentially a problem in the future that CPM is an example, where fast may not be best.

00:30:33 DR. JERRY SULS: So, I'm wondering in regards to speed, though I understand the idea here that patients might very much want closure very quickly, I'll think about a - somewhat similar situation another area in which people are anxious and that's money.

00:30:54 Around the whole question of finances and money, and no one I would think - no one would want to go to a

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financial counselor and talk for 45 minutes to an hour and make all of their decisions about the future based on those 45 minutes and a good financial counselor should schedule a series of meetings.

00:31:15 So, I guess the question that I have is whether though that this may be coming from patients whether in fact a series of discussions or clinical encounters is something that you think is a feasible thing to do with sort of graded decision making along the lines or is that really something that's rather really unrealistic in the current medical climate?

00:31:44 DR. STEVEN KATZ: I think there's - there is I'm hoping that there's an opportunity to slow this process down and build more cognition into it. I'm actually, a little bit worried about it because even as we are building tools with great - so we're building decision tools which is a comprehensive decision tool, which looks nice, and take patients through the decisions both the local regional and systemic therapy.

00:32:15 We've had tremendous response from clinicians, surgeon practices that were deploying this in the trial, no

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surgeon practice has turned this down. They don't have anything like this, they want it, and the surgeons think that the patients need it. They feel that there's a lot of information that can densely compacted in that first encounter, many patient's don't hear it.

00:32:38 And they themselves speak a lot about the need for these things but when you go into the trial as we've started up it's going slow because it's hard to get this stuff out in front with the patient at the time in which they are making their decisions. Many patients when they looked at the tool that we are building and we actually engage patients quite a bit to help us build it, said I wish we had something like this - I wish I had something like this when I went through the decisions.

00:33:04 On the other hand, when we are actually dealing with patients or in the heat of that - the decision making it's hard to get that out in front. Furthermore, in practices as you know there are not a lot of incentives to spend a lot more time with patients. On return visits, two or three may not be looked at

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favorably in terms of filling up a slot that would take a new patient, this kind of stuff.

00:33:29 You don't hear this much from clinicians but certainly the system does in favor slowing down and returning visits and phone calls and so on in terms on just how we financially incentives. So, there is a lot of things that do favor the quick decision making but I think that most important is the intuitive response to a threat.

00:33:49 And I think it's a little difference than finances. I think that when the illness threat, whether it is cardiovascular disease but maybe more do intently the cancer diagnosis, it does set that intuitive judgment process in play and I have to say you know the literature on this. It's, we can study until the death of the issue of intuition but influencing that intuitive judgment process is really challenging.

00:34:15 DR. JERRY SULS: Sure.

00:34:18 BILL KLINES: Steven, this is Bill Klines [ph.] speaking. I kind of want to go back to your point

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about the decisions being made in a very quick way. In some ways, there is a assumption that is a decision and once it's made, it's made. I wonder about the liability of decisions made by patients. To what extent in your experience, are decisions made and then reconsidered and remade and so forth? Because obviously, that's an important thing to know when trying to access how much time to give a patient to work through that to eventually arrive at a final decision.

00:34:53 DR. STEVEN KATZ: Well, I think there's two ways. I'm not sure, I to have you clarify this. There's the issue of looking back on the decision that you've made, that can't be taken back, which are most of the decisions around the breast cancer treatments. The one that really can move forward, I can think of two decisions that are in play a year after, it can be the restriction, the breast restriction decision.

00:35:17 It also can be whether I want to continue to take my hormone therapy, my endocrine therapy pill every day, you know So, I think that you can confront that decision. A woman confronts that decision when you

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looks into the mirror about the issue of whether she would want to entertain restructure or restructure can be entertained later.

00:35:37 And of course, they are staring at the pill for five to ten years is another decision that most people make in their lives about whether they want to continue that. What we find on the other hand is the issue of regret around the decision that is already made, we're finding that in the terms of the issue of regret that there's a small proportion of patients who revisited decision prominently, they've moved forward with no regret regarding the decisions that they've made.

00:36:06 Part of that of course is accommodating, we accommodate the decision we make in retrospect and don't want to revisit those issues. Does that get to some of the issues that are you raising.

00:36:20 BILL KLINE: Yeah, absolutely. It's just an interesting thing to think about decisions, not outcomes but a process right and to some extent a lot of work done on decision making focuses more on the outcomes than the process. Despite the fact that the

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process may be equally important. And there are all kinds of biases in the decision science literature like outcome bias that suggests that people evaluate the quality of their decisions by the process even if in some cases it's not appropriate.

00:36:50 DR. STEVEN KATZ: It is a very good point in this case because patients have, you know, if you think about this a month after the decision is made they - they're not going to die - very few women, thankfully die from this - again we're talking about the more favorable prognosis patient population.

00:37:10 This is now half of patients diagnosed with the invasive disease today. Their probability of dying after completing therapy is very low at five to ten years. At ten years and the quality of life jumps back quite nicely, I mean not completely. We've actually done some work looking at employment outcomes as a function of whether you did or didn't get chemotherapy, showing that chemotherapy can result in permanent job loss in women with breast cancer.

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00:37:39 But quality of life is primary impacted in whether they did or didn't get chemotherapy and courageously women, most women bounce back, a vast majority at a year and the quality of life looks no different than those who did not get treated. So, what do they appraise? What is the outcome for them?

00:38:01 Your point is well taking and their outcome is often reflecting back on what is the process was that they went through, both the delivery of it but also the decisions around it.

00:38:13 BILL KLINES: Great. Thank you.

00:38:14 DR. STEVEN KATZ: But, that process is important.

00:38:17 STEPHANIE LAND: Somewhat different point or related to a comment you made a minute ago about the decision when they look at a pill and are continuing, you know, need to take Tamoxifen or another drug for five years, and they're probably are terms for this in decision science but that's not my area, so I don't know, but I think there are two levels for that kind of decision.

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00:38:41 One is yes, doctor I will take Tamoxifen for five years but then we may as we say, vote with their feet. We know that adherence to Tamoxifen hasn't been very good. So, I don't know if that's something that you're thinking about or studying as well? It's sort of two levels of yes, I'll go on a diet, but right now I'm going to have this donut. That's kind of multi-level decision making.

00:39:09 DR. STEVEN KATZ: Yeah, I have - we are at a position we're prominently studying what happens right after diagnosis. I'm really very moved, very moved by what women tell us. First of all I'm moved in the context that the diagnosis, we send them complicated questionnaires about all aspects of their life of this treatment decision making including in the last survey having them estimate what's the probability that they will die from the disease after therapy.

00:39:43 And when we asked that question, there were some concerns that we would upset patients, it would hurt our response rate. But I will report that our response rate on the first about 2,000 patients that where we fielded the survey question in the context of

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a larger survey that we had gotten very high response rate, 95 percent of women returning the survey have actually answered that number from zero to 100. And what's really moving to me is the partnership that you get from patients in the middle of their treatment when you engage them about their treatment experience.

00:40:18 So, it's predominately the first year of their experience, but we've also done some follow-up survey to the survivorship period. Not many decisions left on the table, that was the point being made earlier. You know, three to five women have left this behind and most women do, recurrence rates are relatively low, quite low in the patient population with favorable prognosis.

00:40:42 And they are left with either doing nothing with very little surveillance or taking a pill and I don't want to overstate or under emphasize what they're left with but it's dominantly the first few months, you know, the first few weeks of decision making and then weathering the storm that they're trying to get through.

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00:41:03 And I'm very moved by that, which is why the slide at the beginning was not a chronic disease but incidents for most women and episodic for a few in this population. And so that first, that first few weeks into the first few weeks is where all the action is. You know, one thing a recurrence of breast cancer is not a good thing. There's not, in terms of distant spread, there's not a lot we can do about that.

00:41:35 So, basically everything we do we rise on the initial weeks of decision making and in some cases a single encounter and then the delivery of that therapy. That puts a lot of pressure on decision making.

00:41:47 FS: Well, I think you were right there to point out that there are also decisions that they're making on a daily basis throughout the coming years if they're on some kind of long-term hormonal therapy. So, yeah, and the main thing is that you also brought up that level.

00:42:04 DR. STEVEN KATZ: About a third of women who get reconstruction do it later. So, about half of women who get mastectomy get reconstruction - about a third

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of those women do not get immediate reconstruction, there is a delay. So, that is another example and breast reconstruction is a very important and complicated decision for women, often left off the table because of all the other decisions to be made.

00:42:27 And complicated in terms of the kind of reconstruction they can have. I sympathize with getting that one on the agenda for them during all these other sort of primary treatment decisions. And so, reconstruction is another one that can come up a little later in the patient's life.

00:42:46 BRAD: Can you hear me? Sometimes my phone doesn't work on these things.

00:42:55 DR. STEVEN KATZ: You sound perfect.

00:42:56 BRAD: Oh good, wonderful. So, my name is Brad [inaud.], we haven't met formally yet, though I know you came to our Center of Excellence for Cancer Communication Research meeting up in Michigan, you're working with colleagues of mine, Vick, and Larry, and others and so it's great meeting you by phone.

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00:43:11 DR. STEVEN KATZ: Thanks for joining up.

00:43:13 BRAD: I have a question for you as you tell when we focus on where all the action is, there is part of the decision making process we do know that it's a very constructive process across many people and I was struck with your presentation where you had all the people that were at the table as the decision evolved.

00:43:34 And we know this happens in the way we fly a plane. Right? It's not one person, it's a lot of people that are contributing the right information at the right time. You're developing tools that support these decisions in better ways. I'm just kind of curious as if you've been able to create support, kind of for a team environment where the - and what they look like? Where the kinds of supports were better and what communication decision making may look like?

00:44:01 DR. STEVEN KATZ: I think it's a great question Brad. I think that in breast cancer, actually in any cancer you can probably draw out who the team - well we've studied, we've actually mapped who's at the table and

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when with regards to breast cancer. This is would be much harder to do, you know, I'm general internist, so I'm constantly thinking about cancer and the context of all health care and this is hard to do for diabetes for instance or other chronic diseases; dementia.

00:44:32 Where you have a moving target over time and you're moving and doctors are coming into play over time, whether it's a different primary care doctor because you've changed, your cardiologist, neurologist, you can have a lot of different doctors involved in your life with a chronic disease over time.

00:44:53 With this incident episodic or incident breast case example we know that 100 percent - so this is what we know, 100 percent of the time all women go see a surgeon and 90 percent of them have their procedure by that surgeon. That's actually a very important issue. So, we're identifying the surgeon who is - so 20 percent go on for a second opinion, but 10 percent, half of them come back to their primary surgeon.

00:45:20 That level of precision, Brad, you know, in terms of what we understand of a surgeon allow us to identify,

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know that a surgeon, a patient encounter is likely the primary decision context for that patient as an example. I was actually, Brad, more recent data, just preliminary data in my hands in the last two weeks, we had on ongoing debate here about what proportion of patient's go on for second opinion for medical oncology.

00:45:49 Let me ask the group this. As a guest, proportion of patients, percentage of patients that go on for a second opinion from their primary first chemotherapy consultation, what kind of numbers do you think we should be looking at there?

00:46:06 FS: I would hope it would be more than 65.

00:46:11 DR. STEVEN KATZ: Sixty-five percent?

00:46:14 FS: Yeah, I would hope.

00:46:15 SK: Other members, please? Sixty-five percent, a second opinions, please? No one? Brad, what's your thought?

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00:46:21 BRAD: I don't know, I would have thought maybe 30, 35 percent something like that.

00:46:27 SK: Okay.

00:46:27 MS1: I thought five percent.

00:46:30 SK: Yeah. Five percent is the winner. I was thinking, well, we know if it's 20 percent for surgeons, because we've studied [inaud.] and so on, but medical oncologist we didn't know this, and so the first thousand patient's they report, five percent reported they went on for a second opinion, which by the way was the guess for several medical oncologist here at Michigan.

00:46:52 So, it's quite low, and so, Brad, another little data point is the medical oncologist they hit, is the medical oncologist they're going to make their decisions with, same with their surgeons. Therefore when building tools, you're really thinking that it's a surgeon who's involved in that patient's life and a medical oncologist that's involved in their patient's life.

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00:47:13 And therefore the tools can be staggered with first your surgeons, this is what we did in our tool development. Tools developed, to be deployed in the surgeons office, because all the patients start there and then patients are encouraged to come back to the tool a couple weeks later on the chemotherapy decision, so not everything is pushed at them at one time and it's kind of a two pronged approach.

00:47:40 You got local regional's decision and then you have a systemic treatment decision. If you look at diabetes or cardiovascular disease there would be no prayer of doing anything like this. But, because breast cancer does have a bit of more structure with regard to that local regional, then systemic, not only that but you got a surgeon, you got a medical oncologist, I think Brad, you'd have no better place to put tools in then in breast cancer across any health care condition, and that's where I would leave it.

00:48:09 Whether patient's are going to allow you the time to peruse that content and come back to the doctor is absolutely empirical question and I'm not so sure that

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we're going to be able to pull that off. I just don't know whether that arm to the doctor, you know, you're in the exam room, that arm to the doctor, or the doctor's arm to you, is how much knowledge base gets in between that. I really think that's a really important empirical question.

00:48:43 BRAD: That's great insight, thank you Steve.

00:48:47 DR. STEVEN KATZ: But I think there's no better place to test this than in breast cancer, because of what we know, Brad, in terms of mapping the way that decisions are made and who makes them with the patient.

00:48:56 BRAD: Yeah.

00:49:01 DR. STEVEN KATZ: But I have to say that I'm fairly as a doctor, as a research scientist, as a patient, I am fairly conservative or cautious about how robust the opportunity is. Because I'm increasingly coming to the conclusion that the relationship factors and the intuitive judgment process are so dominate in these, in these - when faced with a health threat like this.

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So, that's almost like a personal opinion at this point.

00:49:30 BRAD: Well, it's interesting that you're mentioning that, because it's something that [inaud.] and I have talked about quite a bit, goes back to in student medicine when they made their recommendation that medicine needs to become relationship oriented. The real kind of engineering context for that, the health system says, is it's not transaction oriented.

00:49:50 That a relationship is something that evolves over time. And, and I think that's what's happening here, is it's several meetings where the patient feels very confident now with that surgeon or that medical oncologist. They know they can tweak the office with at least a telephone call if there is something important and if that gets violated, I think that's when we see people going off the grid with a liability claim or something like that.

00:50:14 DR. STEVEN KATZ: Thank you.

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00:50:18 MS1: So, Steve, I wanted to ask you, there was one thing you said in your more formal presentation and I didn't quite track it and that is where were you seeing the role of the electronic health record, which you mentioned?

00:50:33 DR. STEVEN KATZ: Well, coming back to Brad's point, you know, we currently have a trial that is a little behind, so we started about six months ago to deploy a state of the art deliberate deliberation tool, both including local regional decision making, tailored [inaud.] University of Michigan tailoring.

00:50:53 So one arm is deeply tailored, another arm a basic kind of [inaud.] website, and we're deploying this in breast cancer, surgery practices in Michigan and in Georgia and with a standalone. You know, in today's times to integrate these things into what we're calling EMR when we proposed two years ago, there was no prayer of that. We didn't even know what these EMR's would be looking like two to three years ago.

00:51:18 So this is a standalone meaning that the patient's go it rather than it goes to them through a electronic

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medical record system that they're a part of. But clearly the next step for these things are what we're calling a virtue a shared learning system that integrates both incoming from patients and outgoing from doctor into something like EPIC [ph.], which we have in Michigan and of course lots of other folks are getting it now.

00:51:46 So, something that's in the patient portal that is more fluent and easier to navigate than, you know, going up on a separate website. Even though actually in the future it might be a separate website because of the relationship between the companies and the institutions, it may still be kind of standalone hosted by outsiders, but integrated into the workflow in a way that works better.

00:52:12 I have to say, I'm not sure that even that greater facilitation in the higher educated group that hits the portal over the next five years that that will yield a lot more uptake of these tools, but that definitely is a question that has to be answered. So the EMR then is just a vehicle to deliver this kind of engagement and knowledge based information in a way

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that probably at the higher educated group in a more facilitated way. It's still unclear about if you build it do they come.

00:52:49 MS1: Okay, thank you. Are there any other questions from the listeners? Okay. Well, Steve, we thank you very much for a great presentation and I think we've had great answers to our questions. Any other details we need to do to finish up?

00:53:21 DR. STEVEN KATZ: Well, I'd like to simply say, thank you very much. I always learn a lot from my NCI colleagues and there is a lot of wonderful science being done intramurally and I think we need to emphasize more this extramural, intramural kind of collaboration and cross fertilization that we get, and this hour was a great example of that.

00:53:43 DR. JERRY SULS: Well, we appreciate your feedback. Thank you very much.

00:53:48 AMOLA SURYA: Yes, thank you to Dr. Katz for your presentation. If you have questions after today's webinar, please email NCI.brpwebinars and ICFI.com or

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call 301-407-6608. Thank you for joining us. This concludes today's webinar. You may disconnect at this time.

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