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<https://reachmd.com/programs/cme/enhancing-your-lung-cancer-practice-applying-shared-decision-making-in-the-real-world/11035/>

Released: 01/02/2020

Valid until: 01/02/2021

Time needed to complete: 30 minutes

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### Enhancing Your Lung Cancer Practice: Applying Shared Decision Making in the Real-World

Announcer:

Welcome to CME on ReachMD.

This activity, titled “*Applying Shared Decision Making in the Real-World: Strategies for Enhancing Your Practice*,” is brought to you by The University of Texas MD Anderson Cancer Center and the Academy for Continued Healthcare Learning and supported by an educational grant from Genentech.

Dr. Elamin:

Welcome to this activity: Optimizing Shared Decision-making in Lung Cancer. I'm Dr. Yasir Elamin, Assistant Professor of Thoracic Oncology at MD Anderson. I'm joined by my colleague, Dr. George Simon, Professor of Oncology at MD Anderson also. We will be joined by Dr. Jack West, who will introduce himself.

Dr. West:

Hi, I'm Dr. Howard Jack West. I'm a medical oncologist and associate clinical professor at the City of Hope Comprehensive Cancer Center in Duarte, California, where I specialize in thoracic oncology.

Dr. Elamin:

Today, we will be discussing best practices and strategies in optimizing shared decision-making in patients with lung cancer in the clinic.

Interviewer:

How can physicians utilize referring patients to online resources and patient groups as a means of understanding different options in alleviating anxiety about treatment?

Dr. West:

I think many physicians have been wary, historically, about referring patients to online sources, including online patient groups, may be worried that they are going to lose their control over the patient and they'll have unrealistic expectations, but the fact is that many patient groups—I would say most—have people who have a lot of knowledge and experience and ideally have control over the kind of fringe element views that are not grounded in good evidence, and it is very valuable for patients to connect with other people who have walked the same path as them. I consider myself as having an expertise in lung cancer, but I haven't received these treatments, I haven't experienced the feeling of the diagnosis, the challenges of managing family issues, etc, but the people who are online have a connection because they have walked that walk already, and that gives them an expert credibility that is different from and extremely valuable for the situation, so I would say that it can provide great assurance. If a patient finds that somebody has been on the treatment that they are about to start and they are told that, yes, it's manageable, and in fact this patient online had responded well, that gives a level of confidence that the greatest expertise that I have and the statistics I can offer just don't match. Our brains are built for stories, and so, for all the statistics we have, people still connect based on hearing what worked for one other person and how they tolerated it, so I think it's not an “either or” but a “both and.”

Dr. Simon:

So, educating patients how to use online resources, in my opinion, actually saves you time, and I actually tend to guide them in how to optimize these resources. The first thing I tell them is to make sure that they are looking at the right diagnosis. I see many patients who will look up a melanoma trial or a lymphoma study or a colon cancer study and ask me questions about whether those drugs are applicable to lung cancer, so I tend to sort of educate them on lung cancer and ensure that they go to the lung cancer specific site.

The second area where they sometimes can go awry is the stage, and I try to educate them that the treatment for stages are different and have different philosophies and different tools. And I often see patients who will look up stage IV studies and try to apply it to their stage III setting. "Why are you not giving me a targeted therapy?" And so, educating them on making sure that they look at the right diagnosis and right stage and look at those resources would actually help you take care of them better. And I actively direct them towards websites from the National Cancer Institute, the American Cancer Society, and in specific situations lung cancer advocacy groups. I also like Dr. West's GRACE blog and other specialized resources like EGFR Resisters and (unintelligible)\*4:32 and a few other tools like that. Directing those patients to those resources and tools actually makes your job easier and also helps allay patient anxiety as to the fact that you are also aware of those and plugged into those, and they can then have a free conversation as to what was recommended in a particular blog or in a particular website and how that can be incorporated into the patient's treatment plan.

Dr. Elamin:

I hundred percent agree, and I think knowledge is power, and it's all about empowering patients to have the right knowledge to be able to make the right decisions for themselves. I'm personally a big fan of patient support groups. As you know, George, we've had great experience with EXON 20 group, for example, or with the EGFR Resisters, for example. These patients get together, share their experience, share the way that they managed side effects, especially from new or experimental therapies, and they also share knowledge about clinical trials: "This trial is open in Houston," "This trial is open in New York," and so forth. And with the EXON 20, we even had the experience where some of the patients put kind of steps of how they managed some of the side effects for some of the new drugs that we've used, and we've actually had one of them to come lecture our other patients about how to manage these side effects. So I do think using online resources is really empowering for patients, and to be perfectly honest, it's educating for us as physicians. They come to you and they tell you that, "We saw this on the Facebook page," and they share this certain post with you, so I find it very helpful, and I think it's empowering for the patients, and exactly as you said, it helps us take better care of them.

Interviewer:

What is the best way for members of a patient's care team to be accessible if they have questions or concerns about their treatment?

Dr. West:

Increasingly, there are tools that are built in—things like MyChart on EPIC—that are available for patients to reach either their physician or the team. Now, increasingly, oncologists, like many other physicians, work as teams, and so I think there needs to be an understanding that it doesn't always have to be the oncologists themselves but the physician assistant or nurse practitioner or other member of the team who is a key member who may see and respond to that. We often work so closely together that there's ongoing communication. That may come through something like MyChart. It may come through e-mails if a practice uses that. Of course, phone triage is part of that as well. And so, when I talk with my patients, I encourage them to write in through MyChart, and I see that or someone else on my team does and we can respond, but if it's something more urgent and someone has significant symptoms they are concerned about, that they should call in because that's going to be the quickest, most immediate turnaround. So those are the key tools.

I think it's exciting to consider a future where there's more active pushing, kind of pinging patients with text or something like that to ask, "How are you tolerating this?" and just push 1 if there's some concern. That isn't broadly adopted yet, but there is some data to show that patients actually do better when we reach out to them, because so many patients tend to be stoic, they want to be good patients and not bother their team, but if they are invited with a low threshold to get back and say, "Hey, I'm experiencing nausea, vomiting," or some other issue, you can address that proactively before it becomes a bigger problem, refine things and importantly, potentially, keep people on treatment longer and have them do better for that.

Dr. Elamin:

There are tools that are built in, tools like messaging or e-mailing through MyChart on EPIC, but with experience I have learned that the method of communication has to be tailored according to the patient's personal circumstances. I have patients who don't have desktops, who don't have smartphones, who like to communicate only through phone, so what we tend to do now is, at the first visit we give them kind of a page that describes how to get in touch with us using MyChart or using the phone, and then we make it a point for the clinic nurse to document which method of communication is the best method. Most patients are comfortable using MyChart, but some of them are not. They like to discuss things over the phone. And, of course, as you know, we're all busy with work, and that's why it's important to build a team and for every single member of the team, whether it's the physician, whether it's the nurse practitioner, whether it's the clinic nurse, to build a relation with the patients so they are able to answer their questions according to their knowledge and to their

understanding of the patients' wishes.

Dr. Simon:

Yes, I agree, and I think engaging the entire team is very important. A few minutes spent in the first visit I think is very well spent, so I typically advise them... I give them the same page that you give, Yasir, and I tell them that, "If you have a scheduling question, this is the scheduler. If you need a letter of some sort, contact the nurse. If you have a prescription refill, contact the nurse practitioner. If you have a medically based question, then call me." And we have one person sort of filtering all those questions and then assigning it to the specific team member that needs to address that question. Of course, if it's an emergency, we just ask them to call in. So I think a few moments spent at the first visit educating them on how to contact the team in an efficient way can really go a long way in trying to make sure it is efficient for the patient as well as for the team.

Dr. Elamin:

Absolutely, because one of the most frustrating things to patients is that they have a question or they try to get in touch with the physician and they can't do that, so I agree with you completely, that spending the time to make sure that they know exactly how to get in touch with their team is absolutely important, and that will lead to a very smooth relationship with the patient.

Interviewer:

What are some ways that physicians can utilize members of the care team to help address concerns about treatment-related adverse events and the diminished quality of life that arises from treatment?

Dr. West:

Many patients are concerned about the toxicities of treatment and a drop in their quality of life, and I think that there is no substitute for connecting with people who are very intimately involved with care delivery. This is often people in the care team that we don't talk enough about, like the infusion center nurses, who are often working with these patients for hours at a time every few weeks, and there's often a bond that is created. The infusion nurses see so many of these patients and talk with them for so long that they really get a sense of how patients are experiencing this, and I think that with that comes a credibility that few other people have. Of course, talking as a physician, as an oncologist with the patient is of some value, but I think there is a great benefit to having the infusion nurses involved with the providing reassurance, saying that they have treated many, many patients on this regimen and know they are doing well. There are often even volunteers who may work in the cancer center who have had cancer before, may have had that same cancer and been on that same treatment, and there is no credibility like somebody having actually taken that medication and knowing what it's like. There are also groups, both live—sometimes in some centers they'll have patient support groups where people can share this information—and online groups where you're not limited by who's available in your immediate geography within your zip code, but you can reach hundreds of people from all over the world and overcome the geographic barriers and find those who have experienced these medications and can provide some reassurance at least in foresight of what to expect, because I think the unknown adds a great deal of fear, so to the extent that we can describe what to expect as physicians, that's something, but hearing it from people who have actually administered that to patients or patients who have received it is, I think, very reassuring.

Dr. Simon:

I think the most important tool that we have in our team is the pharmacist. And every time we start a new drug, I tend to make it a point, as does every member in our group, to actually go and sit down with the patient and educate the patient about the drug, about the potential side effects, and even give them a written handout in nonmedical English so that they can understand the potential side effects of the drug and what to expect and when to call and what are the duration of those side effects and the intensity of the side effects that one can expect. So I think being forewarned is being forearmed, and keeping them with the tools to recognize the side effects and call early is a good way of mitigating some of the adverse effects of some of the drugs that we use.

Regarding quality of life, I do tend to advise my patients that an untreated cancer is a toxic condition, and the cancer can cause a lot of side effects and problems like fatigue and pain and other things, and with treatment and response to those treatments, the quality of life may actually improve, not deteriorate. Often I've seen patients who come in a wheelchair and you start them on a TKI and now the next visit they are walking into your clinic and say, "I just had 8 rounds of golf 2 days ago." So the quality of life can go down sometimes with the side effects of treatment, but quite often it can actually improve as you respond to the treatments and you get tumor control. And that being said, it's still important to recognize what are the potential adverse effects that can reduce your quality of life and how we can mitigate them.

Dr. Elamin:

I agree with you. I find probably the biggest 2 concerns that a cancer patient would have during their first visit is, number 1, the prognosis, and number 2, the side effects of the treatment, so this is a very big concern for cancer patients. Especially with the older regimens that we use as chemotherapy and so forth, that has created the reputation that cancer treatment can be often very toxic, and

that's why every team member has a role in addressing these fears and addressing these concerns for patients. And I agree with you; a pharmacist would typically play the leading role; but also, we should also think about other members or not directly members of the medical team, like as I said earlier, patient support groups. Those are groups that have had those medicines, that have been through this journey, that they have experience. That is very important in helping our patients who will be taking the drug to deal with it, so I also encourage my patients to try to get in touch with these patient groups or follow their pages on social media.

Interviewer:

What is one strategy a physician can use to reassure a patient that they are up-to-date on treatments and potential clinical trials that can be used to advance their patient's care?

Dr. West:

Physicians do need to convey their knowledge of the field to provide a sense of reassurance to the patient, and with that, I think it's helpful to talk with authority about the latest information that has come out in a journal article a few weeks ago or talk about findings from a meeting that they just recently returned from. That is not every physician, and so in other cases it may be saying that they have talked with their colleague who is an expert and only treats a specific kind of cancer. That could be through e-mail, or, "I was just on the phone with my colleague who's at the university who reassured me that this is the exact right treatment." It could be just reviewing online content. There are many ways to do that.

Another is, of course, to offer a second opinion. That could be an actual real referral to someone across town or in another part of the state. It could be a remote second opinion. Increasingly, we're offering tools like sending in records and having a written consultation or a phone call or telemedicine-based visit. So these are their options that actually, in my center at City of Hope, we're building and trying to make more readily available for people to not need to travel for that and make it an expectation that you'll get a second look, that reassurance of somebody who has a subspecialty expertise who eats, sleeps, lives and breathes breast cancer, lung cancer, etc.

So there are many ways to do it, but I think that the key is just to tell the patient that you have been looking at the latest information from the journals, from the last meeting, and been in close communication with others in the field.

Dr. Elamin:

What I do to reassure my patients that they are getting the best possible care and the best possible recommendation is that I review with them how I reached that decision. So, for instance, if I'm recommending a TKI, I'll be reviewing with them the recent clinical trial that was presented at that specific meeting and what were the outcomes and what are the other trials in the same context, so going with the patients through the available evidence would make them understand how you reached that decision, and that will show them that you did not make that decision or take it lightly, but you've done it after a lot of research, a lot of studying.

The other thing that I also tend to tell my patients—as you know, George, you're at MD Anderson—most of our patients would go through what we call the tumor board where a big group of physicians would go through their medical record and go through their images and then reach a decision, so I tend to tell my patients as well about this process, and I'll be telling them, "I'm going to put your name and discuss you through the tumor board, and that would be the decision of the group." That's especially important in complicated cases with complex history.

Dr. Simon:

I agree. I think patients are looking for clarity from their physicians. If the diagnosis and treatment is straightforward, communicating that to them clearly in an understandable way and backed up, like you pointed out, with the right studies and the right presentations would be very helpful to them. Often the situations are not very clear. Like you pointed out, there may be a multidisciplinary team that is involved, and how to involve the different tools in an optimal way could be controversial, so in that situation I think it is important to reassure the patient that you will engage the team and then use our collective wisdom or heads to come up with a treatment plan, and tumor board is an excellent tool for that. Sometimes I use an e-mail chain where I include the surgeon, the radiologist, the radiation oncologist, myself and any other team member. We all sort of form an e-mail chain about that, and I can communicate that to the patient. And the patient, when they meet the different team members, understands that everybody is on same page, and that is very reassuring to the patient. So, when the patient sees that from the confusion of a diagnosis clarity emerges because of a team approach, that is very reassuring to the patient.

Interviewer:

Patients who conduct additional research on the treatment plan advised by their physician generally end up with a positive perception of the treatment plan compared to those who do no additional research. How can a physician help encourage this through resources beyond requiring time from the physician?

Dr. West:

Cancer is very high stakes, and it certainly makes sense that patients would have concerns, trepidation, about a treatment approach that could be a life or death decision for them. With that, I think there is a great reassurance in patients finding corroborating evidence, and this can be in various ways. I started, a little over a decade ago, a cancer education online nonprofit called GRACE, Global Resource for Advancing Cancer Education, and that's all free information. So patients can go online, potentially find information from people who aren't their own physician and find corroborating evidence that sounds exactly what they were told by their physician, and if they get that, it's reassuring, and they buy into it with a lot more satisfaction. That may also come in the form of discussion with people in online groups who have a similar situation. It may also be a second opinion. You can go and get an opinion from a center across town or across the state. You can potentially do a remote second opinion that involves a telemedicine visit or sending your information to a center and having a phone conversation or just getting a report back that summarizes the recommendations. These are all ways that you can triangulate the options and ensure that what you're hearing from the local physician is in accordance with the same kind of recommendations coming from others and I think would give a greater sense of confidence and buy-in and satisfaction for the patient.

Dr. Simon:

So, in a situation like this, I tend to sort of take the patient's educational level into consideration. If I have patients who have a lower educational level, I tend to clearly give them a treatment strategy, and then I tell them why I'm giving them the treatment strategy, even quoting a recent review or a recent article or a recent presentation. As patients become more and more educated, I may go up the echelon and give them a reference, and even sometimes I print out the paper and give it to them so they have it in hand. I also send them to other resources that they can easily search out, resources from the NCI, NCCN, American Cancer Society, the ones that we mentioned. And if they have a specific disease or a specific entity—like you mentioned, Yasir, about our EXON 20 group—there's also for EGFR, general EGFR mutations for ALK and for RAS, so they can communicate with their peers as to the side effects they are facing and the efficacy they are expecting.

So I think doing that actually gives them satisfaction, a sense of security, and also in a way makes our jobs easier because they have a lot of their basic questions answered, and then when they come to us, they have their 1 or 2 important questions as to why did we pick alectinib versus brigatinib, for example, or any other questions like that. So I think it's really in the best interest for everybody concerned, all the stakeholders concerned—the patient, the physician, the physician's team—to ensure that the patient is as well-educated as possible.

Dr. Elamin:

I agree with you. I always tell my patients that knowledge is power and that for them to have the right knowledge and to have the right resources at their disposal would make them help me make the right decisions and have the right plan, so I completely encourage them, exactly as you pointed out, to websites like the NCI, like the patient advocacy groups and the patient support groups, where they could find the correct information and educate themselves about their disease and about their treatment and about their options, and I find that's really helpful. I find that makes my conversation with them much easier. I find that makes it easier for both of us to reach a mutual decision around their future care.

Interviewer:

What are some feasible steps or routine practices that physicians can use to apply shared decision-making principles in today's care setting?

Dr. West:

One practice that I would recommend is that physicians ask patients to recite back some understanding of the treatment they are getting and why they are getting it, and this just assures that they have internalized this and also that they have a good enough understanding of what they are pursuing. A second would be to offer online resources that could be helpful for a patient, and this provides an openness, a transparency, and also gives them license to look online rather than just say, "Don't look online; it's all terrible;" and also helps direct them to the places that can be most trusted, the places that have information that is provided by ASCO or other cancer experts like cancerGRACE.org. And a third would be to ideally have a separate time in a visit or a separate visit to go over the recommended treatment approach in the context of potential alternatives. In my centers we've had informed consent discussions, and the patient needs to sign a form. This certainly lends itself to that kind of discussion. It's not usually the first or only time people have had it, but it's really a consolidation of our discussion of the pros and cons of what we plan to pursue relative to the other options, and so I think having a compartmentalized time to frame this and just make it a routine that people always have this kind of discussion ensures that shared decision-making is executed, and it's going to lead to better patient satisfaction.

Dr. Elamin:

I think the first step is upon us as physicians to accept this as a new culture and to make it into a new practice, so accept it and make it a point that we're going to adopt it in our daily clinical practice. The next step would be to devote time for SDM, so if you're seeing a patient for the first time, you have to make sure that you've changed your template in a way that this visit is longer. If a patient is coming

back for a scan result where a decision is going to be made around change in treatment or around prognosis or around best supportive care, make sure that they have longer time, so I'd say tailor your template to take these things in accommodation. And I think we're lucky at MD Anderson that we have this luxury of changing our template. So, if it's a short visit, just checking on toxicities, 20 minutes can be enough. If it's going to be at the juncture of treatment where you're going to make decisions, take that into consideration in your template and make it a longer visit. I think the third step is again empower a patient, give them the right resources. If you educate them, if they have the right knowledge, then they will be able to make the right decision that would suit their values, their preference and their philosophy in life.

Dr. Simon:

I agree with you entirely, Yasir. I think those are very good points. I think incorporating the SDM strategy early on with your first meeting is very important—it makes it more efficient for us and for the patients—and then eliciting questions: “Do you have any more questions? Is there anything else I can answer for you?” And I would argue that the time spent initially educating the patients and giving them the resources will pay off longitudinally over time as things become easier, as patients develop a more detailed and in-depth understanding of their disease and their prognosis and what to expect from their treatments. The follow-up visits actually become much more efficient, both for the patient and for us. So I think it's a tool that needs some upfront investment, but the payoffs are down the road.

That concludes this activity: Optimizing Shared Decision-making in Lung Cancer. Thank you for joining myself, Dr. West and Dr. Elamin. We hope this discussion has been useful for improving the clinical experience between physicians and patients. Please make sure to complete the posttest to receive CME credit. Thank you.

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