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Shared Decision Making in Today's Clinical Reality

Announcer:

Welcome to CME on ReachMD.

This activity, titled "Shared Decision Making in Today's Clinical Reality," 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

When a clinician hears the term shared decision-making, they may think that it takes too much time and effort in an already too short time frame during a patient visit. What are some current realities facing physicians as it relates to their clinical practice?

Dr. West:

I think one of the challenges that physicians face when considering SDM is all the other pressures in their daily lives and practice, and the reality is that oncologists, like many other physicians, are pressed increasingly to see more patients in less time. We have documentation demands with EPIC and other electronic medical records, and that needs to be done basically through the course of a day, orders need to be signed, and so shared decision-making, while a great concept, is one that I think some physicians have some resistance to just because of the concern for the added time it would take in a world where it's harder and harder just to get through things that are expected because we're having more turnover issues, you have very limited amounts of time, and so can we do this with the time that's available to us.

Dr. Simon:

In the current clinical practice context, there is clearly increased demand on physician's time. Physicians are required to see more patients, document at the same time and allow time still to interact with patients in a fruitful manner. There's also a shortage of oncologists in the country, and then that is compounded by a physician burnout problem that has been recognized throughout the country. Given all these constraints and all that being said, I think SDM is still important to ensure that patients are allowed to participate in the decision-making, and SDM practices should be incorporated very early on in the discussion with the patients so that the time is not just optimally utilized but also very fruitfully utilized.





Interviewer:

What sort of infrastructure at a physician's institution or hospital can support shared decision-making?

Dr. West:

I think that the institution itself needs to really buy in and make it a priority, ideally even to articulate this as an expectation and incentivize it in some way or at least to create the tools that make it easier to succeed. That can involve things like having scribes to help with the documentation when docs are in the clinic. It could include building in smart phrases that can help make it easier to document shared decision-making, because I think one of the other challenges is that you can have these conversations, but if they're not documented, they are considered to not have happened, and so it's not just doing it but documenting it—so scribes, building in smart phrases that can make it easier to put that in, and training in this and just helping articulate the expectations, giving written materials or videos or live training to help oncologists be able to integrate this into their daily routines.

Dr. Elamin:

I agree with Dr. West that SDM, for it to work, it has to be integrated and become part of each institute and each hospital culture, and for that to be integrated into the daily practice of a physician, I think resources like training the physician and the advanced nurse practitioner should be provided. Videos and algorithms that would help the physician to go through the process of shared decision-making would be helpful as well to physicians to get more and more used to this concept as we help our cancer patients go through their journey of treatment.

Dr. Simon:

I agree. I think this is a situation where we can borrow a page from the heart surgeons. A heart surgeon, a senior heart surgeon, usually has the patient's chest open by a team and closed by a team. He's present during the critical portions of the operations, so his critical skills are utilized optimally while his support staff open and close chests and give routine care. Similarly, in this context the oncologist's time can be optimally utilized if some of the support staff and physician extenders can take over the role of going over medications, answering routine patient questions, answering scheduling questions and logistical questions, leaving some of the key decision-making questions to the oncologist. Ultimately, another way to sort of decrease the load on the oncologist is for routine clinical visits where just the labs have to be reviewed and the patient go on for further chemotherapy could be entirely taken over by physician extenders leaving the oncologist free to deal with the situations that need critical decision-making.

Interviewer:

Might some physicians believe that shared decision-making allows the patient to dictate to the physician regardless of a physician's best judgment? If yes, how can this be overcome?

Dr. West:

There are some physicians, I think, who may be concerned that shared decision-making implies some greater autonomy for a patient that could be threatening, but I would say that this doesn't need to be the case, that you're not going to, as a physician, present options that are poor ones. The concept is really to present and discuss the options throughout a continuum of reasonable ones that may not necessarily be the absolute top choice for the physician but would include ones that are certainly in the range of what would be reasonable and then integrate a patient's perspective on their own personal priorities. So I would say that this should not lead to any expectations that a physician would be expected to give a treatment that they find inappropriate. If somebody doesn't have kidney failure, they don't get a replacement kidney; you don't get a kidney transplant. There is always the bounds of what is appropriate medical care. This just is a change, a shift from a prior more paternalistic approach where the expectation was that a physician would tell the patient what they should do and the patient should nod and except that, but now to say, "Well, we can think of these 2 or 3 options. They are all reasonable and have pros and cons to them." And this allows the patient to provide some input, make a selection and buy into this plan.

Dr. Simon:

I always viewed patient decision-making as a partnership. It is taking into context the clinical realities combined with patient preferences, and you understand the patient preferences, and using the current clinical realities and situations you come up with a plan that is optimal in the setting of what the patient wants, so in a sense it's always a partnership, a mutual decision-making process. Most physicians that I know of don't have the "my way or the highway" attitude. It's always trying to come up with what is the best treatment option for this particular patient who is going through this particular situation, and that by definition is an essential component of shared decision-making.

Dr. Elamin:

I agree with this, and I think it all comes down to that training ourselves as a profession that our care going forward is going to be centered about the patient, and it's going to respect their philosophy, their views, their personal preferences. So it's not as if patients are





making medical decisions. No, they are just picking from a continuum, as Dr. West said, of all valid clinical options and picking what would soothe their social circumstances or would soothe their background and their understanding and their philosophy on life. So I think it comes down to that idea that we as physicians have to adopt this new culture and see how it's going to improve, ultimately, patient care and lead, hopefully, to better patient outcome and patients be more satisfied about their care.

Dr. Simon

I agree. And sometimes the patient may actually punt the decision to you and ask you, "What would you do, Doc, if you were in my position?" In that context you're free to give them what you think is the best treatment option for them.

Interviewer:

Might some physicians be hesitant to share specific information about treatment options to patients? If yes, which ones are most common? Why may this be the case? And how can this be overcome?

Dr. West:

There are going to be some gaps in what a physician presents to a patient, and that's based on all sorts of things. It may be that the physician just doesn't know what a certain treatment is going to cost, and that is because it may vary from plan to plan and over time and individual circumstances. There may be unknowns just in terms of toxicities, particularly when a physician doesn't have a lot of experience with that. I think there is a concern that physicians may filter the options that are presented to those that are available at that center and the ones that that physician has the greatest experience with, and for that it does make sense if a patient has heard the options and they might have some awareness of a different option through outside learning on the internet, etc., well, they can get a second opinion. They might also ask the physician for a recommendation for someone in the area to give a second opinion that would either corroborate the choices that have been presented to them or maybe offer others. So, yes, there's always a limit in what is being presented to what is recommended, or at least within a range, and a patient is certainly entitled to try to clarify how those recommendations match with other things they may learn about outside of that setting.

Dr. Elamin:

I think that most physicians tend to share all the information that they know with their patients. Of course, there are some limitations in some cases like a physician not having the familiarity with the treatment or the physician not having the necessary knowledge in some areas, but in most cases I think that they would be willing to share most of that information. Having said that, I do think that patients, especially in this time, tend to educate themselves about their diseases, tend to go to the web, to the internet to learn more about their diseases and about their options, and in that context I think bringing back the information they gather in discussions with their physicians is going to be very helpful. Also, considering getting a second opinion might be very helpful in that scenario.

Dr. Simon:

Yasir, I agree entirely. The standard of care is pretty much uniform across the country, and there may be some variations in its application, but it's generally standard across the country. Where I find a difference or a dichotomy is in clinical trials, and we as a group are very good about offering our patients clinical trials that are available at MD Anderson. Sometimes our patients are traveling from 8 hours, 9 hours away, or even a 4-, 5-hour plane ride to come and see us, so over the years I've become cognizant of that and have tried to educate the patients about possible clinical trials that they may have available closer to home or at least give them the resources to search out the clinical trials that are available to home so they can minimize these long travel times and other ancillary expenses. I think the big differences come in the menu of clinical trials that are available in a particular center or in a particular state or in a particular region, and the patients should be encouraged to communicate with their local oncologists and also see what resources they have locally compared to the resources and clinical trials that are available at our institution.

Interviewer:

Do you find that patients are comfortable or confident sharing their hopes and expectations for treatment?

Dr. West:

I would say that many patients are extremely confident, confident enough to want to interject that really from the beginning first visits trying to talk about their priorities, their goals, and I think that's very appropriate. Sometimes they have already been online and have read about things that you should talk about with your doctor, questions you should ask, and are emboldened by that. Beyond that, I think that they certainly tend to be very inclined to talk about it when they are invited to by the physician. If the physician asks anything about, "Well, what are your priorities?" they will overwhelmingly be gratified and inclined to share that information and incorporate that into their decision-making.

Dr. Simon:

Patients are almost always very honest when you invite them to give you what they expect from their treatment and hopes and expectations, and as we are actually reasonably good at trying to educate the patients what to expect from the treatment and from a





scientific standpoint the response rates, the progression-free survival, what kind of side effects to expect, but what we want from them is what are the goals that they are looking for. "I want to go for that cruise" or "attend that high school graduation" or "attend that wedding," and it's good to know what those kinds of plans are, because I sort of encourage patients to let me know what their plans are so that I tell them that's important and we can adjust our treatment schedules accordingly.

What I've had more trouble with, actually, is sometimes them being a little bit more honest with me about the side effects they are facing and the challenges they are facing with an ongoing treatment. Some patients will try to hide that from me in the fear that I might recommend discontinuation of treatment or reduction of the dose, which could then lead to decreased efficacy. Surprisingly, I found that they are sometimes more honest about those kinds of things with my nurses and nurse practitioners, so I tend to sort of encourage them to ferret out the kind of experiences that they have had with their previous chemotherapy and then tell me what's going on, and then I confirm that when I see them, but in most cases patients are pretty open about their hopes and expectations.

Dr. Elamin:

I agree with that, and I think when it comes to their hopes or the big hopes over the long-term journey, the long-term prognosis, the long-term treatment, whether to have treatment or not, I think we as physicians have a duty to try to build trust, to try to build a relationship, to get them to be more open about their hopes and their expectations and their values, and this is something you kind of learn by experience. And I have to admit that as much as I try to educate my patients, I'm learning from them, I'm learning about their personalities, and I'm trying to build the skills to use them with my next patients when it comes to their respect, and I'm trying to get them to open up about their expectations and hope and how they want to be treated and what they are hoping to be achieved. So I think we as physicians have a duty to try to educate ourselves, to train ourselves to build that trust with the patients so we come up with a really shared plan that would combine the knowledge of the physician and the expectations and the values of the patient.

Interviewer:

How often do patients communicate their preferences and priorities for treatment, and is there a place for it?

Dr. West:

I think there's a lot of variability in how comfortable patients are in stating their preferences up front and articulating their own goals, and this is really based on many things. Some of it is individual. There's a fair amount of generational differences, and historically, medicine has been more paternalistic. In some older patients and in some systems like the VA, there may be more people who say, "Just tell me what I should do, Doc," and that's okay if they just don't want to interject their views. But many younger patients, I think increasingly, expect to have more of a say, to learn more and be active participants rather than passive recipients of care. This is absolutely appropriate, and we've really moved as a field of medicine from a more paternalistic approach to one that involves shared decision-making and recognizes there's often not one absolute best treatment approach but a range of choices that are reasonable, and this should integrate the preferences and the personal circumstances of the patient.

This is the direction that things are heading in, and I think many patients—and if not the patients, their sibling or their children—are trying to enable an active voice for the patient, and it is a good place for things to go, in part because you'd never get more buy-in than when the patient is part of that process, and they really feel they understand why they are doing it, so I think this leads to greater satisfaction. And more than that, that's what the evidence shows.

Dr. Elamin:

I think Dr. West is making a great point. There is a great variability among patients on how often and how they feel comfortable communicating their wishes and hopes and preferences to their physicians. As he indicated, some patients would rather just follow what the physician is saying, tell them, "Just tell me the plan," and they proceed with that, while others tend to be more engaged and try to discuss various options. I find that some patients also use the help of their family members, whether it be a wife, a husband, to get the message across to their physicians, so you'll have a relative or a family member who's more open about the preferences of the patient and kind of the psychological state of the patient, their toxicity profile, so there will be more communicating with the physicians. Again, I think the physicians have a duty and have a responsibility to try to navigate through this, to navigate through the patient's personality, the family dynamics, to try to reach out and find out the information that they need about their patient's preference.

Dr. Simon:

I agree, Yasir. I think it's somewhat the physician's responsibility to ensure that he or she understands the preferences and priorities for patients, and usually, they respond to that fairly honestly, especially if there's a caregiver and family around if you directly ask them that question: "What are your goals?" "Here are the results from the—expected results from the treatment. And given those results, what are your goals?" "Would you like to get treatment here or closer to home?" "And what kind of treatments would you prefer?" What I found in my practice is that once it's laid out that way, they pretty often frankly communicate to you what their individual preferences and goals are.





Interviewer:

How is communicating with a newly diagnosed patient about treatment options different from a patient with recurring disease?

Dr West

It's always important to consider the context for the specific patient when doing our communication, and one of the bigger issues is whether a patient is newly diagnosed versus has been working with this diagnosis for a period of time and is in a recurrent setting. With newly diagnosed disease, patients are often overwhelmed and just don't have the background information or the tools yet to process everything. And so we often hear that you talk about the diagnosis, and once you give that information that you have cancer or it's metastatic, everything that comes after that is a blur, and so we need to be very mindful of that and ask patients to repeat back what they have heard and what they understand. We may want to have additional visits after that so that people can process it, give written information so that people can have it at home with them or offer videos or some other tools so that patients don't need to be relied on to retain everything after that first mention of the diagnosis. Ideally, also, if patients are accompanied by family members or friends, they can help take that information in.

In contrast, if patients have been dealing with a diagnosis for a while, they may have a greater understanding not only of their current situation but of the future options. I try to talk with patients not just about here's the treatment we're on now but here's what we would be thinking about in the future if the scan looks great or if the scan shows progression and so they are better equipped to process the information when it comes. They may have anticipated and learned about a subsequent treatment option beforehand. So, ideally that's going to be the case. Certainly, cancer is one of those diseases that lends itself well to patients learning about their disease because it's high stakes, but it tends to be ideally longitudinal and somewhat chronic and enables people to learn more about their situation in the light of day.

Dr. Simon:

So, in the initial visit, it's all about educating and engaging, so you are trying to educate the patient as to the diagnosis, the stage, the implications of that stage and what are the future treatment strategies, and then you want to engage the patient in the treatment decision-making. A recurring visit, on the other hand, is more about informing and then possibly educating, so you tell them what the latest results are and what your future strategy is and then, if necessary, educating about that strategy for subsequent treatments. One of the things that I've learned is, one of the most important anxiety mitigators for a patient is confidence in their oncologist. If they are confident in their oncologist and know that the oncologist knows his stuff and is acting in their best interest, patients tend to be less anxious and tend to be more open for suggestions and treatment recommendations.

Interviewer:

Is communicating with the lung cancer patient about treatment options different between one who is a smoker compared to a nonsmoker?

Dr. West:

I think that there are only modest differences in our approach between a smoker and a never-smoker. One key point is that nobody deserves lung cancer, and we really want to somewhat tailor the message here. I have some patients who have a smoking history who have such guilt that they feel like they don't deserve care, that they betrayed their family, and they are just overwhelmed with the stigma and the guilt of it. And so one important aspect is that, yes, you smoked—but often times people quit smoking a long time ago, maybe decades ago—nobody deserves lung cancer. You deserve to be treated, and here is how we move forward. In a never-smoker the discussion is a little different, and it is largely around, "Why did this happen?" "Why me?" And it's a discussion, of course, that they don't deserve cancer, it's unfair, but trying to explain the genetics and the things that we are still trying to understand about why a never-smoker would get lung cancer and put it in the context that it is less rare than so many people think, and there are plenty of other people, including those who can relate to what they are going through, who they can connect with and I think really help them cope with this challenge.

Dr. Elamin:

I don't think there is a major difference in communicating between patients with a history of smoking and those who are never-smokers. Having said that, I do think from the patient perspective there are major differences. In my experience, never-smoker lung cancer patients always have the question: "Why me? How did that happen? I've done all the right things. I have never smoked. I'm keeping a healthy lifestyle. Why me?" So you have this challenge of trying to address that and get them to cope with that, the fact that a disease like lung cancer is historically linked to smoking and now we're seeing a change in the demographics of lung cancer where we're seeing an increase in never-smokers. So I think the physician has to address this question and this frustration around, "Why me?"

However, when you're talking about the patient who's a smoker, the challenge is different, because those patients, as Dr. West pointed out, tend to have guilt, feeling that they have kind of messed up, and here it's important to get the message across that, exactly as Dr.





West said, no person deserves lung cancer. And irrespective of the smoking history, all patients need to be treated with dignity. They need to be helped. They need to have the best options that are available for them.

Dr. Simon:

That's very well put, and I agree. I think all patients, regardless of the smoking status, should be treated with dignity and respect. I tend to understand the smoking status purely because there are some signs associated with it in terms of the probability of having mutations and actionable targets and the tumor mutational burden and other technical aspects. Because of those technical aspects, I try to understand the smoking status of the patients, but beyond that, smoking status has very little value in treatment decision and patient management.

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.

Announcer:

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