An Introduction: Share Decision Making in the Clinical Practice

Presented by Vicki Olson

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Welcome to the introduction to shared decision making conference call. At this time all participants are in a listen only mode. Later, we will conduct a question and answer session. Please note that this conference is being recorded. I will now like to turn the call over to Vicki Olson. You may begin.

Thank you. Hello, everyone. This is Vicki Olson. I'm a program manager at Stratis Health, the Medicare Quality Improvement Organization for Minnesota and I would like to welcome you to this call and it is intended for providers working with quality improvement organizations in Alaska, Colorado, Kansas, Minnesota, Montana, Nebraska, Nevada, south Dakota and Wyoming. Our featured guest speaker today is Dr. Lawrence Morrissey. He is the chair of our Minnesota Shared Decision Making Collaborative, a group of stakeholders that are interested in the advancing the use of shared decision making in Minnesota. He is a pediatrician and Stillwater Minnesota and has a long standing interest in improving the patient experience. His work has help reflected that passion. I have had the pleasure of working with doctor more see as part of the collaborative and he is knowledgeable about the nuances of implementing shared decision making and what is happening internationally and nationally in this area. I will turn the presentation over to you, Larry.

Thank you very much. Vicki. Thank you, everyone, for taking the time to listen today. Just to give you a little bit more background about me, I am a general pediatrician in Stillwater Minnesota. Our clinic provides primary care provider and specialty provider care and we have been working on various forms of implementing shared decision making in Stillwater since about 2006. It has been a great experience to try to find the most effective ways to help collaborate with patients. I hope as you listen to me talk kind of understand that I bring with it sort of real world perspective of having to do this on the front lines and even though I do do some research, I'm not at a university or anything like that, I'm there every day trying to do the work and I'm hoping to help you try to see practically how this is important in your practice and also give you a sense of kind of why it can connect with why people get into healthcare and really engage their passion for trying to do the work that makes a difference. As I'm talking, hopefully that will be the case.
I will start with the objectives. We are here to help you understand the key components of shared decision making and what are the principles that underlie that patient centered care, learn about some practical elements of the patient and provider experiences shared decision making and why it is important and especially kind of how people go about making decisions and understand kind of complexities to that and specific things we assume are happening but really don't necessarily happen as much as we think they do.

And then talk a little bit about some strategies that we found to be effective in implementing shared decision making in practice. As we think about the idea of patient centered care and we look at the definition, there are a couple of specific terms I want you to think about more carefully as we are considering this concept. The words are patient preferences and patient values. Values is a term that has an overarching meaning to a lot of people. It is kind of like the word family. You say "family" and people have all kinds of different ideas what it means for their family. Being specific talking about values in this context, values is defined as kind of an after averaging approach that a patient would make. If I had a value that I said I want to avoid having surgery unless it is absolutely necessary, that would guide me in making decisions in multiple different context. It would be something I would carry through those different situations.

In one situation, I might end up deciding that surgery is necessary because of the specifics of that situation and in the other I might not to. I might choose not to have a mole removed because I think it might be cancer and I might not choose to have my knee replaced. It is not hurting me bad enough to go through the process of having a major intervention. A patient preference is more specifically oriented toward a certain situation. I might have a particular feeling about how I would want to handle colon cancer screening as I look at the different options that are available to me. It would be affected by my values but my preference would be pretty specific to the unique nature of that situation. And these preferences influence our decision making and they are not always conscious. Sometimes they need to figure out how to communicate them as they are trying to make a decision. Let's take for example, Mary. Mary is 70 years old and has been just diagnosed with early stage breast cancer. Her medical history is complicated by the fact that she has diabetes and walking is difficult for her and transportation is difficult as well because her husband recently passed away. Getting to and from doctors visits is difficult for her. This decision she is faced with treating her early stage breast cancer has a lot of medical components to it. There are two options that she might consider. One would be to have a lumpectomy and have only the area around the tumor to be removed and the other to have the entire breast to be removed. The need to do lumpectomy might require radiation treatments over a long period of time. As she is considering her decision she needs to weigh-in the other factors, her diabetes and how that affects her risk of having infection from the surgery and her transportation issues. These might not be at the forefront of the mind of her surgeon when contemplating the treatment of her cancer.

There are two experts in the room. The doctor has a strong knowledge base about the treatment options and the medical evidence surrounding the options that are available to Mary. At the same time Mary knows what things are important to her and how is she going to be able to be successful in executing the treatment plan that is laid out before her. The two experts need each other in order to have a good conversation about how to best go about approaching the problem and like many situations in medicine, there is not one right answer. Some patients choose option A and some patients choose option B and sometimes we get stuck in the mentally that there is one right choice when either option is reasonable based on the medical evidence. This is a study from Lee that looks at how people feel about the priorities in this situation. They asked a group
of patients who were faced with early stage breast cancer and a group of providers who were caring for patients with early stage breast cancer, what things do you think is most important. They gave them a list and asked them to pick the top 3. And it was -- you can see a large percent of the providers felt that that preserving the breast was in the top 3 important things. There is a marked disparity that in this sample a very small number of patients rated keeping the breasts in the top 2. Living as long as possible was important to both groups but there is a significantly larger percentage of the patients -- of the providers who felt that living as long as possible was one of the top 3. I think the most interesting column here is the third one. The patients felt strongly that doing what the doctor says was the right thing to do was in the top 3. It is not a surprising place for patients to be because you have been diagnosed with cancer. You are scared. You are not knowledgeable about this. And you have the sense of wanting to defer decision making to someone else who is knowledgeable. Where I think there is a real challenge, in this environment where patients are deferring and uncertain, the providers are coming into the decision making process with some preconceived ideas that maybe aren't necessarily aligned with what the patients think are the most important thing. Those issues of not being aligned can maybe steer people down the wrong path and if the providers take the time to ask the patient what do you think is most important and help the patient understand that there are multiple options that help them achieve their goals, then you give the opportunity for the patient to become more actively involved in the decision making process and not have the sense of needing to defer.

So this is one of the take home slides. This is the summary of what we would think of as the central components of shared decision making. Both sides need knowledge and in particular, the patient needs to develop an understanding of this decision that they are faced with. We as health care providers have gone to school for a long time to learn about this stuff and very often patients are thrown into making a decision without having fundamental knowledge about what they are deciding about. Understanding the options that are available to you as you are trying to make a decision is really important including having the understanding that doing nothing is an option. It may not be the best option. It may not be the best option but doing nothing is a choice that people will make and sometimes not intervene is the right choice. We need to make sure that in these conversations there is a discussion of risks and a discussion of the benefits of treatment. And I think in many discussions we think this conversation involves a clear risk and benefit when it really doesn't and a lot of studies around shared decision making when patients are asked knowledge questions that assess whether or not they understand the risks and the benefits, a lot of times they are not able to really successfully answer those questions. In particular, patients want to understand risk but we often use terminology like using percentages that confuse people rather than making it more clear and having a more effective strategy to communicate the risk and benefit is really important in the process .

The final piece is that understanding patient values and including them in the decision making process is something that needs to explicitly happen and sometimes it doesn't happen the way we think it will. Sometimes when it doesn't happen, providers will move into this term knowledge -- [ indiscernible ] when in reality, it will be that the patient's preference wasn't really clearly understood and that's why the patient has not chosen to follow the plan we laid out. Why is this important? These decisions are complicated.

Patients are struggling and need guidance, a little picture there is how Splitrock light house in Minnesota and having something that helps the ship see where the cliff is is really important and the reason why this light house was built in the middle of nowhere is because one winter in 1911 three ships sank within a few miles of the outcropping of rocks and after they built the light
house, the area became much safer. So giving people guidance and letting them see a way without assuming they understand the risks and benefits is a really helpful thing in order to make sure that patients can make a good choice. I will have you think yourself here about the basics of how you go about making the decision.

We will try to take a step back from the medical world where things are complicated and go to a couple things in a lot of ways are perceived as being easier. If I were to ask you the can you stop on your way home from work today and pick up some milk, that seems like a fairly easy choice. As you contemplate what I just asked you to do, your brain has probably already moved very quickly to what store you would buy the milk at and what type of milk you would buy and how much and how much you would be willing to pay for it. The interesting thing we do -- and we can't do this on a webinar -- I will have people write down what milk they will get and then ask them to hand it to their neighbor and exchange the details of the milk that they will purchase. Almost without exception you don't get the same milk. There is an enormous amount of options. Although we make the decision relatively quickly, we have a lot of factors that we take into consideration that reflect our personal preferences in that specific decision and the only way we would be able to get the correct milk for our maybe is to ask. So one time when I gave this talk and I had the question and answer session at the end, one of the doctors raised his hand and says you know, I really don't understand the milk slide. How am I supposed to know what somebody else wants unless I ask them. I said that's exactly the point of the slide. When we were looking at the treatment choices that are available, part of what we need to do is ask and understand what people are looking for.

This is another more complicated decision about where you would live. We have all been through this in some way or another. Particularly when you go to buy a house, you will go through a process of making a decision and incorporating a gain and knowledge about something which you are not familiar and then including your personal preferences in the process of aligning what you want with what is available to you. The other thing you will do in this situation is incorporate what your family members want. If your -- if you are living alone and maybe you live close to your mom, it is easy. If you have a wife and children like I do and you are trying to decide what house you will move into, that decision becomes complicated because others people's needs and preferences need be incorporated. The next thing is you will go to a closing and sign on a dotted line and agree to pay for a house that you have bought. There is a lot of paperwork there and you don't necessarily always really understand the documents as well as you would probably like to and a lot of times you rely on somebody else to help you understand it so you don't get stuck with something like a house that has a bad foundation or a leaky basement. In the end you feel engaged and you feel empowered to make a good decision about the choice that you made and you choose to get to a place where the house that you have purchased and the documents you are signing is aligned.

We have a medicine that is supposed to achieve that same goal, a document. That is called informed consent. Prior to having a procedure, the patient should be informed of the risks and benefits of those. You will find that many studies show that informed consent in the words of a friend of mine, neither informed nor consent wall. A lot of times patient's understanding of the information they are signing for is really not where it needs to be. I put a couple of examples here that I think for our hospital colleagues can be disruptive. Less than have -- that's not necessarily a good number -- in particular, before people's understanding of information about potential risks is often very poor. So in this study by sheer, a reasonable number of people had recalled in a discussion about surgical outcome but a declining number of people were able to name any specifics about the potential risks involved with the surgery and the more detail you
ask them, the less they remembered. I think this is a place where it is difficult and a lot of times people are getting the information relatively close to when the procedure is happening. A way to think about shared decision making is it is taking the delivery of the information upstream and getting the information to people earlier in the process. So they have a better chance to think about it, understand it and utilize it as they are trying to make the decision about what to do. I think there has been good work about surrounding how to make this better and improving the ways that we communicate information to people is going to be a really helpful strategy to try to make things closer to what we would want to see.

Decision aids is particularly encouraging piece of that data. This is data. At that time there were tools that showed that it led to better patient knowledge, less feeling of risk, less uncertainty around the decision and the decisional conflict. People struggle with that in terms of what does that mean. If you are faced with the decision and you feel to a sense you don't know what to do, that is what decisional conflict is and if you can reduce that and give people a greater sense of confidence about the decision, that helps them as they are going through the process. People participate more when they have had decision aids and in some situations like PSA testing, there are studies to show people are less likely to choose intervention. Part of the challenge here is what is our ultimate goal. When you talk to people about shared decision making, this is a place where there are a lot of different ideas of what we are trying to accomplish here. You will see people talk about shared decision making in the context of trying to lower cost other lower utilization. You will see other people talk about it in terms of helping patients become more compliant with the treatment plans that we are laying out for them. There are some states and some situations, particularly Washington state has a law that says if you do shared decision making you have greater protection against being sued. I try to help people take a more simple approach. That is this is the right thing to do for people. The idea that we want for people to be well informed and part of why we want to do that is that we want to help them. We want their needs to be met in a way they feel confident and comfortable about. Unfortunately, it doesn't always happen as consistently as we would like it to. I will try to transition away from the theory of this and give you a sense of more practical things you can do as you are thinking about trying to have shared decision making be part of the work that you do.

This is a picture of the foundation of an addition to my house and kind of a prompt for me to say that ultimately kind of the organizational attitude and approach towards the problems that you face need to be in the right place and they are the foundation upon which you are going to build the work that you do. And you have a good sense within your organization that being patient centered that putting time and effort into this area will be worth while because it aligns with your vision and what you are try to go accomplish as a healthcare provider, that is a great starting point in terms of moving the work forward. Then just like every other quality improvement project that you do, you have to pay attention to the process that you are going to put in place and it sounds -- a sound process that supports what -- the goals you are trying to accomplish is fundamental in order to be able to be successful and if the work is not integrated well and to the process you are doing, it will fail.

Then the third element is what tools are we going to use to help achieve the goal and that can come in the form of decision aides. It can come in the form of health coaches. It can come in the form of increased education about the providers for needs that the patients have in that area.

This next slide is a universal slide because the barriers I list here as you look through them, they apply to every quality improvement project you have ever done and I think the most important is the first one. There is a strong consensus among healthcare that I do this every day. When you
start to learn more about shared decision making and start to understand what is involved in it, then you come to a realization that you are probably a lot farther away from the goal that you aspire to than you really believe. It takes some time for people to come around to that but helping them see the examples of where they kind of take their own values and kind of prune down the options that are made available to patients to the things they think are reasonable sometimes helps them understand you don't always do this in the way you think. I think back to the Don Henley song. Time is always problem and people feel cramped for time and -- cramped for time and the perception is your decision making will take more time. In reality sometimes it makes things go faster because if you do a good job communicating, the interaction can be focused on making a decision rather than be focused on communicating the facts. If the patient comes in with a better fund of knowledge at the start of the conversation, you may be able to make the conversation more efficient.

Cost is always a barrier and these things do in some ways represent a cost. Although I think relative to the cost of other things we do, it is pretty small and it may -- that cost may reflect some extra nursing time or the time it takes to find the right decision aid to give to patients or make a decision aid for patients. But in the end when you look at that cost relative to the cost of some of the interventions that we do. It is pretty small and probably a worth while investment especially if it can lead to people feeling like the process was a better experience from the patient's perspective. It is another thing to do on an endless to do list of things to do and patients sometimes have a little bit of a hard time because they may view other things as a priority and sometimes we have to work with them to say I need you to give me this feedback and kind of illicit that from them and make them feel like their contribution is valuable. For both sides that can be a change for the nature of the role. Whenever you are introducing change, then you can be viewed with skepticism, people would like to keep doing things they are doing.

The final thing is how fast -- I go from being a good idea to a proven entity. Being able to establish that you can effectively do this is a challenge. I don't think we are there yet. The way to get there is to work on it. If you went back 15 years ago, you didn't necessarily have a good pathway to do a lot of different things that now we have studied and learned about and can do more effectively to the challenges we are facing. There are a lot of different ways to get from Manhattan to Brooklyn. You can go before the visit and get the patient before the visit and you can give them information during the visit and after the visit. You will see people in favorite methods of trying to work with the patient and I try to take advantage of other opportunity like we do with other quality efforts to make sure we are doing the right thing.

This slide is also kind of universally acceptable as a quality improvement slide. It is a team effort and it is not just about making doctors do things differently. There are lots of different ways that you can go about helping to provide patients with information with the effective strategies that involve of the physicians but also involve other people on the team. But if the -- the key is to be consistent, you have of to have a sound process and working that out and understanding the details of how you will understand how people will understand the information that they need will be important. In Stillwater, we started very small. My first project was with patients with uterine fibroids because it was part of a research project and we have about 60 patients to work with and it went onto prostate cancer and I had one our rolling gist. I was able to get 100% buy in and one meeting because I had one guy to convince. You can build on that success. As we have moved this work with shared decision making out into our organization over time, we have relied on the success stories of those smaller projects to get people to get excited about the concept and be willing. That is a really important piece as you are going forward to tell a good story. We are careful about the tools we choose. I will not go into a lot of specifices about
which tools. You want to be thoughtful about the information and one of the things that people work on shared decision making have noticed is they -- provider buy in about the content of the tool at the start of the project. That really improves the willingness of the providers to participate and that is a piece that whatever topic you choose as a starting point, let’s make sure we are all on the same page about what information we want the patient to have is a really good starting place. And it does require willingness to change and you have to kind of work within your organization to find the places where people are willing to try to do things willingly and take a chance. It is not an easy thing to do but one physician was pretty courageous, why I couldn't say and he wasn't sure in the back of his mind it was going to work. He had his doubts but was willing to go along with it partly because he knew me and we were friends and partly because he had the courage. He left me this voice mail about a week into the project and it was very memorable moment because when I heard the voice mail come on, I thought he is going to call and tell me he doesn't want to do this anymore. In fact, what he said was Larry this is amazing. It is totally changing my practice. It is making me more efficient, more effective, helping me connect with the patients more. I really want to keep going with this because I think this is a great thing and we were able to build on that momentum and kind of change how he approached his job and it was a wonderful feeling to know that you made things better.

The last thing is you have to measure. There are ways for you to go about trying to measure what you are doing, including measuring patient knowledge, measuring how the team feels about the process of the implementation. I think ultimately one of the things you need to measure is does the patient feel like the decision that they made is that consistent with what is important to them? It is a hard thing to measure but it is important that that is kind of what our ultimate goal is. A couple other practical pieces of advice, timing is very important here. Especially in situations like patients who have breast cancer, it takes time and support to make sure that the patient is ready to deal with the decision. The idea that we use or phrase we would is a warm hand off where we try to use people like an RN care navigator to make sure that the patient feels supported through the process and that when they are ready to take in the information, we are there for them with that if the patients feel like they have the time to get comfortable, then they can come back and ask better questions and feel more confident and we can encourage them to express their own preferences and values so we can get them to a place where we can feel more engaged and more involved in the process.

There are tools out there. We have a group of people in Minnesota that like shared decision making. We formed the Minnesota shared decision making collaborative. It is a bunch of people who meet quarterly who meet to see how we can make shared decision making happen. We have put together a website. We are in the process of building it it still. We are trying to get tools and information out to people so that if you want to make shared decision making part of your plan, you can have the road map of how to get there. Ultimately part of what you need is to be able to know it is feasible and that the lines -- it aligns with what you are trying to do and part of of what you need is sort of the practical pieces of advice, the version of this power point is on the website that you can download and use for yourself. Another really helpful website which is not on one of these slides but if you Google OHIRI, they have good tools that can give you information, Mayo clinic has good tools, Dartmouth has good tools. There are a lot of places out there where you can get good information about shared decision making and that is something as you are trying to learn more about this, those are other resources that you have available.

That's the end of my talk and I'm willing to open it up for questions.

We have time for questions. Operator, can you remind our attendees.
We will now begin the question and answer session. If you have a question, please press -- if you are using a speaker phone, you will need to pick up the hand set first before pressing the numbers. If you have a question, press star and 1 on your touch tone phone. If you have a question, press star and 1 on your touch tone phone. At this time I'm not showing any questions.

You want to talk a little bit about the whole idea of starting small with the particular topic area or kind of implementing it just through patient experience.

Sure. So one of things as you kind of look at your topic of what you might want to do is there are many other topic areas that you already know are on the radar screen that could involve shared decision making. I will use as an example treatment options for colon cancer screening. It is something that a lot of people are paying attention to. It is an important area of healthcare and helping patients understand the options that are available to them in that area are very important. The options of colonoscopy versus something like blood testing are quite different and people will need some help kind of understanding that and a lot of patients are a little bit intimidated by the colonoscopy because it is an intervention. If we can in part help them understand the benefits of that intervention and make sure that they are not maybe over estimating the risks, that is an important piece.

At the same time, there are cultural considerations for that treatment choice and for some people, the other option is a more reasonable thing as a way to go about screening for colon cancer. You can take that little nie it is of learning about presenting options and begin the process of getting people more familiar with the -- talk about how do I help you understand your risk of getting colon cancer and how do I get you to understand the possible reasons why doing a colonoscopy might be more convenient for you even though it is more work up front.

The other thing Vicki is talking about is the patient experience element of all things. Many people are looking more at patient experience as part of what they are trying to do and patient engagement is a hot topic. As we look at helping people make decisions, one of the things we hope to influence with that is feeling like they are listened to and that things were explained in a way they can understand and we are using that motivation of wanting to give patients a better experience as fuel to encourage people to work on something we know they need to improve. You are identifying a goal and trying to help them see that the goal that you have aligns with the goal they have and that's something that can be powerful in terms of helping make it easier to get the buy in whether it is from leadership or whether from providers to spend the time working on a topic that they might not necessarily have considered to be a priority.

As we talk about conditions, what would you think are the top 5 that people are working on nationally?

The term that Vicki used was -- this idea that there are some interventions that we do that are maybe shaped by whether or not to do them is driven by people's preferences rather than the medical evidence is important. For example, whether or not you are going to get your knee replaced is driven maybe more by how much symptoms you are having, then necessarily any purely objective criteria or whether or not you are going to have an intervention for something like pros at the time particular high per trophy will be driven more by the symptoms you are having. Unfortunately some of these conditions see that the frequency of intervention is driven by the availability of the surgeon rather than the actual patient's preferences around the procedure and the Dartmouth Atlas has documented pretty well that there is ab enormous amount of
variability with how often certain interventions occur and when we look at those, a lot of times the driving force behind that is the dollars rather than the patients. I mentioned a -- the doctors rather than the patients. The popular ones are treatment options for prostate cancer, treatment options for early stage breast cancer, knee replacement and hip replacement and back surgery is another one that a lot of people spend a lot of time thinking about and some of these procedures may be over used and sometimes it is not so much that a procedure is over used but rather that the patient's preferences will play a big role in what you ultimately choose and we need to be more careful to make sure that the patient preference is driving the decision about the procedure and not just whether or not there is somebody available to this realm is easier to look at in a sense because when you are looking at the options that are available to patients, most of the time there are multiple reasonable choices based on medical evidence and if -- in the case something like prostate cancer treatment, one of those options can be to not treat and it depends a lot on the specifics of this patient situation and the degree and nature of the cancer. But it is a tricky thing because people don't always kind of look at it that way and recognize that. So these conditions are popular things for people to work with rather shared decision making and a lot of the research around shared decision make something focused on the different topic areas.

If you have a question press star and 1 on your touch tone phone.

I'm not seeing any questions.

Why don't we wrap up. We know that shared decision making is a big cultural change for a health care facility, whether it is in a medical group or working in the hospital setting or nursing home or other health care setting. Do you have any closing advice on how to approach making the cultural change with providers, what kind of things that you are working with the Stillwater Medical Group you found was successful in working together as a group in implementing shared decision making?

I think the most important first step is to have leadership buy in and making sure people understand that everything aligns well with what the organization's goals are. In order to carry that torch, you will have to find a champion within the organization who is committed to taking on the charge of of getting people interested and enthusiastic. It is a pretty easy sell when you look at what is the organization's values because I think being patient centered is an attractive thing to put focus on. Not only am I able to get influenced this thing that is a fundamental value for our organization but it will also be able to get into the clinical world of a problem that we know we need to do better. If you can create that kind of compelling energy to say this is a place where we know we can do better, all of the sudden, people will start to come on board.

Thank you for this presentation. The webinar has been recorded and will be shared with your state quality improvement organizations and be available to you. I want to thank all of you, all the organizations that participated in this webinar and I guess that concludes the webinar.

[ Event Concluded ]

If you have any questions about this webinar, please contact Stratis Health, info @stratishealth.org

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