Counseling Across a Lifespan: Adult Patients and Their Families, presented in partnership with Salus University
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- [Christy] At this time, it is my pleasure to introduce our guest speaker who will be presenting Counseling Across a Lifespan, Adult Patients and Their Families, presented in partnership with Salus University. Dr. Kris English is Professor of Audiology at the University of Akron. She has authored several books and chapters, and has presented over 400 workshops and papers in North America, UK, Europe, Australia and New Zealand, primarily on the topic of audiology counseling. Her service to the profession includes 10 years on the board of Educational Audiology Association and five years as a board member of the American Academy of Audiology. She created and writes for a web forum called advancingaudcounseling.com, and welcomes submissions from students, and faculty, and practitioners. Thank you, Dr. English for being with us today, and at this time, I hand the mic over to you.

- Thank you, Christy, I appreciate this opportunity to talk to our colleagues across the country and probably around the globe as well, maybe asynchronously. I am very happy to be picking up the ball from Cheryl DeConde Johnson’s talk yesterday when she was exploring the counseling issues, the psychosocial adjustment issues of school-aged children, probably toddlers too, I don’t know how far back she went, but I’m gonna pick it up from there, a more typical patient, probably 90% of our patients, at least in the U.S., are adults, and we want to make sure that we are helping them as best as we can in a way that may not have been part of our training. That wouldn’t surprise me at all, but we’ll start off with the concept of patient-centered care, we will weave our way through that, and then Part Two is what I would consider the second half of our talk together, it will be family-centered care. So with regard to, oh, let’s take a look at our learning objectives, excuse me. By the end of this course, you will be able to list four interactive components of patient-centered care, list three positive health outcomes associated with family-centered care, and also describe how change affects patients, families and we, the clinicians, basically we hate change and we have to work with that, that’s the answer to that one, quickly. Well, I wanna start again with, as I mentioned, with patient-centered care, which is sometimes not as clearly understood,
as one might think it is. I’d like to give you an example that I picked up on on a listserv, where someone had indicated, "Hey, today, I just fit a new hearing aid," I will just call it XYZ, "with a new patient today." And the response in the listserv was this, "Well, I’ve heard about that one, it’s brand new. "What was your patient’s reaction?" The first audiologist says, "Well, it doesn’t matter, "I know it will work well." So you may see where we’re going with this, there’s a bit of a problem here, the audiologist, the second one, responded to say, "Well, sure, but in the spirit of patient-centered care, "her input would have been taken into consideration, so." And then the first audiologist understandably got a little defensive, "My decision is completely patient-centered, "it’s based on what I know is best for the patient."

There’s something that’s a little bit awry here, and we want to clarify it, not just for this particular interaction, but for all of us in our minds, because we do get into the habit, the routine of clinic, and we maybe forget what do we mean by patient-centeredness? We’re not the only ones that might be thinking there is no clear definition. There’s some citations that I provided here to indicate the people have perceived patient-centered care to be poorly conceived, that there’s no consensus on what it means, does it mean that the room is painted in soothing colors, does it mean that we provide emotional support, does it meet shared decision-making, all of the above? Well, in fact, there is a very good definition that most people fall back to time and again, you can google it and find the Institute of Medicine with this particular document to help us with the definition, what they’re looking at is a set of healthcare goals across the lifespan that have six characteristics, the first two are safe healthcare, and then effective healthcare. Those are so terribly obvious, don’t you think, but it had to be put in writing, I suppose. The third one that we’re gonna focus on is patient-centeredness, what’s the definition? They call it care that is respectful and responsive to individual patient preferences, needs and values. So talking about values, it’s not something that audiologists are necessarily used to doing or are comfortable with, but in fact, that’s what patients are telling you, "This is what I want, this is what I need. "This is what I don’t want to do," those are based on their values, in terms of their lifestyle and other characteristics in
their life. And then also ensuring that the patient values guide all clinic decisions, which is not what we saw in that little anecdote that I pulled from a listserv there. So how do we actually implement that? I want to bring attention to a book written by, well, edited by Moira Stewart, she's part of a team up in Canada who have been working on this particular book on "Patient-Centered Medicine: Transforming the Clinical Method", it's now in its third edition, and I have editions One and Two and I can see their evolution over time. They’re saying it’s one thing to have a definition, but how do you execute it, how do you operationalize it in your clinic? And what we're going to do is take a look, first of all, at there four interactive components, and then see how we might apply this to audiologic practice, because they’re looking at medical care from the physician's point of view, but it really is irrelevant, healthcare is healthcare. So our first interactive component would be to explore not only the health experience, but also the disease and the illness experience, which we'll explore there, then understanding the whole person, finding common ground, and enhancing the relationship between the patient and the clinician.

Okay, I mentioned that we don't have direct applications, we can extrapolate from Stewart’s work, I just saw her mentor being cited as one of the leaders from 35 years ago, defining and expanding upon the concept of patient-centered care, so I think we're in good hands here. So let's see how far we can go. Number one, the first interactive component is exploring the health experience, the disease experience, and the illness experience. And these are very different, but some of them are our points of view compared to a patients' point of view. You might be quite familiar with asking a patient from the get go, a brand new patient to your clinic in your practice, to say, "So what you're here today," and I know you're not gonna clamp on the headphones before they answer you, it's just a funny picture I like, but if we were to start there, we will effectively invite a story from them about what's been going on, what other people in their lives have been saying, what they think about it one way or the other, but they're not saying, "I'm noticing my 2,000 hertz "is not as quite as acute as it used to be," they're not talking like an audiologist, they're talking about the life that they're

continued
living with the changes in their hearing. What we wanna be doing is, we are listening to their first reports of what brought them here today is note that we are, ostensibly and legitimately, collecting the case history, what do we know about their health and all the rest of it? But if they tell us enough, we won’t have to pull out a checklist and make sure that we have got all the details right, we wanna be taking a look at when do we come across what I thought about as a conversation crossroad? When a patient were to say, "Well, my family dragged me here, "they say we're really having problems "with being able to communicate on the phone "and even while we're in the same room together." And we might leave it at that, but in fact, all we've got right now is the patient’s experience of what the family says. So I would call that a crossroads, because we don’t wanna give the family all the report here, all the power to the story, but to say, "Tell me more about what they are actually saying, "some examples, for instance," and then the crossroads part would be to kind of veer off to say, "Well, what is your take on it?"

And what if we could become quite interesting is because that patient hasn’t necessarily said so, until we ask, and then they might find they might feel comfortable enough to say, "Well, I think they’re all nuts and it's not a problem, "everybody mumbles," or they might say, "it's actually been on my mind, too, "it’s been bothering me for a while, "but I didn't know quite what to do next about it." And so, in other words, we don’t know until we ask, "Where are you in this story, "because you're often off putting it onto the family, "and that may not be the full story?" But how do we get to the bottom of all of this story, ‘cause a new patient may not feel comfortable enough, or be able to trust the situation enough to kind of bare their soul. But what we can do, very legitimately, very comfortably, is discuss almost any self-assessment in our field here, but not in order to measure a handicap score, how this is affecting your work, but what are your thoughts about your answers? So I’m gonna give you an example from a classic, and I know you can't see this small print, but I will go to and enlarge it in a moment, but the "Self-Assessment of Communication" by Schow and Nerbonne from 1982, is a classic one, it’s short with 10 questions, and it has a certain amount of
categories. The first one is the situational, what do you notice in different circumstances? But what's the stroke of genius, in my opinion, are the next two sections, what are your feelings about the communication issues, and what do other people say? So if you take a look at the number two, under our feelings about communication, it's one of my favorite questions of all time, does any problem or difficulty with your hearing upset you? I like this because it just says your hearing, not your hearing loss or your hearing problem, 'cause we haven't gotten that far yet, but your hearing, and then the word upset is so terrific because it could mean anything. It's personally defined when a person starts describing what upset-ness means to me, I probably could not have predicted what it would mean to them until we get to that part. And we'll find out where were their stand on that. And then where the other folks in their lives are standing, we can explore that as well.

And again, it's not about assigning a number to a one-to-five scale and coming up with a handicap score, but it's an invitation with open-ended questions to say, "Well, tell me more about this, how are you handling it? "Is it once in a while?" Actually that's a close question, isn't it, sorry about that, just an invitation to expand on the story. And, "Tell me more about what you're experiencing "what you need me to know." So a very good example right there, especially that one question. The next one I wanted to highlight, "Do others suggest you have a hearing problem?" Again, we can get really specific there and find out what it is, but also, "How are you handling that, are you agreeing with them, "are you also overwhelmed with other problems as well "that we need to know about and not focus only on the ears?" Those follow-up and open-ended questions, these are some examples that, "You've helped me understand your family's concerns, "but what are your thoughts?" Or another way to go about it, "So you're thinking about hearing help, "sometimes it helps me to know why now, "has something specific happened lately?" So in other words, it's been called the salient moment, was there a bit of a crossroads moment in one's life where one said, "That's enough, "I've really got to do something about this," 'cause it really does help us that there's a specific impetus. One patient I recall, had said, her salient moments, that's not what
she call it, she just said it was the last-straw moment, was sitting in the front row of her daughter’s wedding, and she realized that she could not hear her daughter and the new groom exchange their vows, she couldn't hear it, and she thought, "This is hopefully a once-in-a-lifetime experience, "and I was stubborn not to try to do the best "that I could for hearing." I'll never forget that example, and you probably have others as well. What we’re basing all of this on is a basic counseling principle that’s multi, excuse me, bi-directional. First of all, we want to understand what patients are experiencing, and we want them to understand what is happening to them, but they also want us to feel understood, they want to feel understood by us as well. So we’re having this back-and-forth experience. Tell me what’s going on, but what is it like? And to know that somebody actually cares about that part of it, helps a patient, if they've come up with a certain amount of resistance, or doubt, or suspicion, about who is this strange person who is now asking me these questions, the guard starts to drop, the defenses start to drop, because it conveys, in very honest and authentic language, that we really do care about the quality of their life, not just their audiogram.

I do wanna talk about stigma, is something that people are a little bit uncomfortable about, but sometimes the elephant in the room is admitting that one has a hearing problem, or also admitting that you might need hearing aids. We know that hearing aids are associated with stigma, may be dropping slightly less, but not as dramatically as people had predicted, that the baby boomers would not have any problems with hearing aids, and we really can't generalize that and be sure about it. But if we are hearing, indirectly or directly, that a patient is recognizing that there is a problem but I'm not about to do anything about ‘em, I’m gonna make sure that no one knows that I have a problem, I’m never going to be wearing hearing aids that people could see, it's wisest to bring it up and address it in person. Some ideas would be to say a few things you've mentioned suggest you might be worried about what other people think about you using hearing aids. The worry about stigma is something, and I'll finish my thought here, is something too many people mention, "Is this on your mind as well?" So what we're doing is going from kind of a generalized observation, and then we're getting a
little more specific about using the word stigma, and then asking, "Is this on your mind, "is this what it has been keeping you back a little bit? "Let's talk about it. "What does it mean to you?" And the reason I'm bringing this up is because the literature on stigma is so consistently saying that once you talk about it, the stigma loses its power, if you keep it to yourself, it has power over you, but after not too long at all to start to say, "Well, I've noticed that these things happen "when people wear hearing aids "and what other people say about them." But eventually, many patients will say, "Of course, that's rather old-fashioned, "or it's a little bit being your own worst enemy, "or shoot yourself in the foot, "and why should I care what other people say? But do you see how that kind of unloads the burden of carrying that stigma as a secret, as it were, and just being another thing to contend with, and saying, "Yeah, I guess it's something "that I have to deal with." There is a caveat to this approach, we wanna make sure that we acknowledge is that not every patient wants to actively participate in these conversations, and we can't make them, obviously, I don't wanna pretend that we can.

I do want to use this last quote here, "Listening to patients, and having them decide "how much they want to participate "may actually be the essence of patient-centered care," which I appreciated when I first came across it to say, "It's your call, we go as far as you go, "I will be with you every step of the way, "but I'm not gonna drag you through anything, "or make you feel uncomfortable at any point, of course." So more about the how to explore this experience of disease and illness. We need to obviously listen but also watch and wait to see what's going on during this narrative. You may have had a patient who is pretty tight-lipped, having not much to share, maybe perhaps glances at the door indication and you're knowing that he would rather be anywhere but with us, and that's understood, we certainly can ask him a little bit more about that. If they are, in fact, sullen and resentful, and they're saying, in so many words, that this is the last thing they wanna be doing, then we just do what we can do and bid them well and ask them to consider coming back when they're ready, but they may be actually telling us things that are hard to talk about. And they may find it hard to say, but people are saying that might be a bit humiliating to them or just reminding
them of other people that that's distracting to them and they are upset, and they start to break eye contact and look away. We wanna make sure that we are comfortable with the silences that follow. They may have more to say, and they just need time to organize their thoughts, formulate how to put this together, 'cause they never said it out loud before. We may need to ask ourselves, too, "Are they asking for advice right now "or they just need asking for some support?" That takes you in two different directions. What their challenge would be is, can we listen without problem-solving, can we wait to see if they can solve it themselves, come to their own decisions on what's best for them, and how to juggle the stressors that they're working with, and can we trust a patient's ability to work through those problems? They probably have done so in the past, maybe not put on the hot seat like they are right now, trying to come up with a solution or an insight, but being comfortable with silence is, excuse me, not an easy process, but I am hoping that the next time you see the opportunity just to wait just a little bit.

I once had a patient who had come to our clinic, age 92, he enjoyed very good health, and looked not yet 70, that's for sure, I would say, and he knew he looked great, and he got lots of compliments, and he's really quite proud of it. And he was accompanied by his wife, who had said, according to the spouse version of the self-assessment of communication, he was having a lot of trouble. He self-reported on the self-assessment of communication that everything was fine. We did his audiogram, there was a not-a-surprising age-associated hearing loss there, and when I took a look at the two self-assessments together and said, "Boy, we have a different point of view, "and I'm wondering what you're thinking about that." He broke eye contact, because he was putting up quite the cheery disposition that everything is gonna be fine, we're outta here we're going out to lunch afterwards. But he said, "I knew she was upset, "but I didn't know it was this bad." And so we made eye contact again and he said, "What would you say about it?" And I said, "Well, "if you need the world to be louder for you "so that your loved wife "can work with you better with communication, "we need devices to make the world louder for you." And he said, "You're talking hearing aids?"
And I said, "Yes." And he looked down at his shoes, and he looked down at the wall, and he looked everywhere else but at me, and then he finally looked at me and he said, "I've always thought of hearing aids "as for old people." And my student at the time, I know in her thoughts, they were, "Dude, you're 92 years old." But it took, I think, probably the count of three, and he just kind of shook himself together to say, "Okay enough, what are we gonna do now?" He just needed to get past that moment, and if we had rushed him through or tried to talk him into it, he might have resisted it, you never know, but I've always said that a memorable opportunity to think, think about waiting just a little bit. Ultimately, what we're trying to talk about is developing a mutual journey that you and I are on the same page to your patient, you and I are not trying to coerce or talk each other into any particular situation, finding out what you want, and I hope you get there.

Okay, the second interactive component is understanding the whole person. I think audiologists are generally thought, favorably in this regard, we do like to know what's going on with everything in their lives, and we do wanna point out that, of course, this is a value supported by the World Healthcare's, excuse me, the World Health Organization, WHO, this is a famous chart, I'm sure you've seen it a million times, the interactive components between not only the number one body functions and structure, but also the how it affects your quality of life in terms of activities and participation, and also the environment that you're in, and the personal factors that you're contending with as well. I think audiology is the generally in sync with this, sometimes we do lose the forest for the trees. After we have identified a hearing loss and a person may or may not be interested in devices, then we may be kind of lose our mind a little bit and get overly enthusiastic and try to press our point in trying to find out instead, where still are we at in this mutual journey? So we've been effectively listening for a certain amount of time, but we wanna make sure that just because we've been listening doesn't necessarily mean that the person who has been communicating with us feels heard. We wanna make sure that we are communicating back to them in every way, verbally, non verbally, that we are absolutely in tune with them. The
evidence is abundant in this regard with regard to the effectiveness of patient-centeredness, and listening and empathy. This is a title that’s one of my favorites, I wish I could have picked it, “Why should I talk about emotion,” it reminds me of this Muppet character. They were talking taking a look at communication patterns associated with physicians’ discussions of patient expression of negative emotions during hospital encounters, what happens when a physician, and we can extrapolate again with audiologists, what happens when we hear a negative emotion and neither ignore it or dismiss it, and at least not acknowledge it, or minimally acknowledge it or actively acknowledge it? And what I will do is just cut straight to, well, here’s the basic details, they had 79 encounters between patients and physicians, and the people doing the research identified 190 times where the patient expressed an emotion about cancer, about a recurrence of a health problem, about other issues going on, and then they took a look at the physician responses and they divided him up into one of three, responses that focused away from, ignored that emotion, they were neutral responses, or responses that actually stepped toward that emotion.

And the bottom line to this particular study is applied to this flowchart, which I really like, it’s so succinct, 190 incidences in that top bar there, the first column is what happens when the physician did not respond and moved the conversation away from the emotional expression? It only happened 25% of the time, that’s encouraging, and what happened was the physician focused away from the emotion. Ultimately, what I was dying to know was, what happened then? And what they found was that there was an instant distancing of the relationship between patient and physician, which is no surprise. If I’m telling you that I’m really upset, and you blow me off, I’m not going to be impressed with you, I’m not gonna be happy, and I may start thinking I might fire you and find another physician. Ultimately there, in some cases, there was actually open antagonism, at that point, because the patient was really hurt. I opened myself up to you and you dismiss it as unimportant, or you’re just poor at noticing. The middle and the right-hand column, are the neutral, or the toward the response toward the emotional comments responses from the physician. In your handout, you can find the
smaller boxes on this, but ultimately, what we noticed was, by acknowledging, and by neutral, I mean just, "Mm-hmm," or just those non-verbals head nods to say, "I'm with you," compared to a toward which is, "Like, I didn't know that this was an issue, "can you tell me more," a little more overt. What they found was that by eliciting the patient's concerns, there was better improvement in understanding, an enhanced relationship, and even a stronger agreement on what we're going to do next, and the more likelihood that the patient's going to agree to adhere to treatment, which is the outcome you were hoping for, but if you don't know what the steps were to get there, a person might have missed them. So did that response make the difference from the healthcare provider, what's the cause, and what's the effect? I'm thinking there is an effect, there is a consequence to how we respond when patients tell us, kind of from their heart, what they're going through, good, bad and ugly. So we're working our way through a process, we may not have recognized it before, but what we're hoping for is to build a positive and direct pathway together on this mutually satisfying journey.

We already talked about the idea of exploration, and then actively understanding, which is where we're at now, so let's take a look at developing common ground, how do we agree on where we're going, that we understand each other in what we're going to do next? Advancing that process is just a natural progression. How do we get there, we might have started off with the self-assessment already. The COSI, of course, is one of the most open, I think it is the most open one where it's, well, it's totally blank, and the patients tell us what they want to put in there. If they don't put it in their themselves, what are their concerns, and how would they rank them in terms of significance? Then we would want to start focusing on where do we go from here in terms of, am I understanding where you are, and then what you want to do about it? The strategies in health literature are varied, there are ways to move forward. There's some discussion in audiology, about the health belief model, but it hasn't really had much uptake. We don't necessarily have the time to explore people's health beliefs, but it is a theory of decision-making. There's also shared decision-making, which I'm a big fan of, I've just been spending a lot of time on this, if you can't counsel a person
well, you’re not gonna get a really good experience with shared decision-making. There’s also motivational interviewing, which is getting some attention in some quarters. But what is easier for us because it’s not quite burdensome at all, is to use some really simple scales, and you may have already seen these from Ida Institute, on a scale of zero to 10, how ready are you, how important, I’ll read this one here, how important is it for you to improve your hearing right now? I like a lot about this, because first of all, the patient decides where they’re gonna rank themselves in terms of importance, but it’s also talking about hearing, improving your hearing, and also right now, maybe it’s something I’m gonna defer for a bit, and maybe there’s some really complicated reasons why, it’s not that I’m saying it’s unimportant, but I’ve got 10 different things that are really overwhelming my plate right now, but I’ll get back to it. So that helps us find that out.

The next one is how much do you believe in your ability to use hearing aids or assistive devices and communication strategies? And again, this is based on that health building model that we can explore quickly, we don’t have to get into the weeds on that. There’s another set of scales embedded within a intake tool developed by the Cleveland Clinic. Here’s some favorite questions I have, range from not very important to very important, you’ll notice there’s no number, it’s just are you in the middle point, or are you at the what closer to one of the ends? How important is it for you to hear better, just in general, number three in this tool is how motivated are you to wear and use hearing aids? There’s not a lot of tools that we have that ask about motivation, but if people are not motivated, and we never ask about it, we may never understand what went wrong by the end of the appointment. The next one is how well do you think hearing aids will improve your hearing? Now, this really helps us because if they were saying it’s really important, in number two, very important, and very important, very motivated, and I also think hearing aids will greatly improve my hearing, now we may have a thought about like a realistic expectations, and just a little thing to file away. We won’t necessarily talk about it at the beginning, but we may know that they may be setting themselves up for an expectation of this perfect cure, for instance, that’s really
not what we meant this to imply. I like this one as well, how confident do you feel that you will be successful in using hearing aids? That has to do with self efficacy. Am I able to handle something new, and complicated, and unfamiliar? Hamlet said it best about 400 years ago, well, Shakespeare said it, didn’t he, that the readiness is all, and no one does anything until they're ready. So we could ask without any scales in front of us, but just from our own mindset to ask a patient as we're moving forward, do we think it’s important to do, to ask, "How ready are you to hear better, to try amplification?" That’s a different question, and a different answer may happen. "How ready are you to try another device? "How ready are you, depending on circumstances, “to advocate for yourself at work?" In other words, if you need to use group devices, and/or Roger Pen or so on, but that’s the last thing you’re going to do, I need to know about that and make sure that I have been informed of your readiness. What we’re looking for is developing this mutual plan of treatment with input from both the patient and the audiologist. This comes from Stewart et al.'s textbook, mutually influencing each other, and you’ve probably already had that experience, that you may be almost one audiologist before the appointment starts and you’ve changed during the course of the appointment because you now have this influence or impression about this patient that changes your thoughts on things. Each of these influences potentially ending up in a different place than where each person began, different understanding, then what would have achieved reaching alone is, and I really appreciate this last line because it will take us to a new point, it’s not a matter of who has power and who does not, it’s a matter of mutual influence.

And that’s takes us to a really important point about power. And I don’t mean Arnold Schwarzenegger power, I mean, control. And what does it mean, when you are a patient who steps into a room not knowing what’s gonna happen, what the person in front of you is going to and do, are they gonna try to make me do something that I don’t want to do? The audiologist right now, at the beginning of these encounters, has all the power. I was quite intrigued when I would ask students, when I first got to know them before we talked about counseling at all, "Imagine that scenario, "you were sitting
down with a patient, "let's say you've already graduated," 'cause right now students don't feel very empowered with anything, "but let’s say you have your license and degree "and the patient sits down in front of you, "who, at that moment, has the power?" And they always say the patient, bless their hearts, I really appreciate that, but in fact, no, patients report that's not their experience at all. The person who speaks of course has power. And what we know from plenty of research from the teams in Australia, Louise Hicksin's folks and Carly Meyer and Ekberg, and there's just a whole bunch of people out there, when they record the transactions, or the interactions rather, between audiologist and patient, the distributions of talk time are so heavily weighted on the audiologist side. What we might think about is can we create less talk time for ourselves and give more talk time to the patient, because then they will have more power? Now how do we monitor that? That's a really challenging question, and you'll have to ask yourself, "Do I wanna record myself at any point, "do I want to just be very mindful "of the fact that I've just been talking a blue streak "for the last seven minutes, and I need to stop "and find a way to turn that over to the patient?" The last interactive component has to do with enhancing the relationship that we've been trying to build from the beginning.

And again, the culmination of our process here that we've been trying to create as a mutual journey. Another quote from Cassell, I really like his work too, "The clinical relationship that we're trying to establish, "it is actually not a brand new idea, "it's been the focus of attention," he would contend, "since the beginning of Western medicine." So we've got a historical background to lean upon. It helps us think about building a relationship as an investment over a very brief amount of time. Unlike other professionals, I think about speech pathologists who see patients week, after week, after week, and they have the luxury of time, we are in a bit of a time crunch, aren't we, to get it accomplished, be worthy of trust in a blink of an eye, almost, how can we indicate to them, from the very first words that we speak, that we're there to provide them support and attention, and dedication, and continuity of care? And if we can't even have continuity of care, can we at least be consistent? In other words, is there
just as no way that this patient is gonna see the same audiologist every time, can you at least say that the process will always be the same, and it always seems familiar to the patient, and of course, the notes are gonna be consistent as well? Documentation, I was mentioning, and that sustainable partnership within the system as well as the interpersonal relationships. Now, if you recall that definition from the Institute of Medicine, that healthcare goals are supposed to be patient-centered, sorry about that, I pushed the wrong button. There we go. And I lost my track. All right, we are knowing that when we talk about patient-centered care, that there are three components that contribute to the evidence supporting it. First of all, as our basic research evidence, we've looked at a couple today by Adams and a couple others, and our own clinical experience plus patient values, just take a look at those. First of all, with regard to the evidence, we would wanna ask ourselves, "Does patient-centered care work, "in other words, is it efficacious?" We've already taken look at some examples here. Do patients want patient-centered care, what are their expectations, and can audiologist provide patient-centered care, is it achievable?

So to the first bullet point, we know from abundant research that patient-centered care is so strongly correlated to positive effects that we could actually count on that x-y axis to look the way it looks, we see a much stronger likelihood that patients will adhere to recommendations, we will find that patients will self-report that their health outcomes are better when they’ve experienced patient-centered care, and actually, objective physiological measures also improve as well. The tricky part is trying to measure satisfaction, we get mixed results on that, a lot of people rely on satisfaction results, which is why I'm pointing it out that maybe we should be a little cautious about them and not market ourselves as all about patient satisfaction, it may not actually mean what we think it means. But how do we actually measure patient-centeredness? This is just a sample of the tools that I come across in my readings. The patient perception of patient-centeredness is the one I’ll be taking a look at in a particular study in a moment, just to let you know that there’s a lot of other ones out there as well. In this particular article, "The Outcome of Patient-Centered Care on Outcomes", published a
while ago, let's see where we are, I don't have the date on there, I'm sorry, but it'll be in your references, not too long ago, from the Journal of Family Practice, they were using the patient's perception of patient-centeredness that I just had mentioned. And what they had done was record interactions between 39 physicians and 315 patients, which I really appreciate that there's a lot of people to tap into here, they transcribed the interactions, and then the patients were interviewed about their perceptions, and then the patient health was assessed by self-report and also chart review, and the physicians’ report, and also two month follow-up data. So I don't think much fell through the cracks there.

The results were these, that the patient-centered communications that were recorded from the transcripts correlated with the perceptions of finding common ground. And that makes sense, 'cause that’s a goal of patient-centered care, and also, positive perceptions correlated with better recovery. Their conclusions, then, were that patient-centered practices improved the patient's health status, and increased the efficacy of care by reducing diagnostic tests and reducing referrals, and reducing follow-up appointments that were reflecting a dissatisfaction of what was going on in the first round of appointments. So, lots of reasons to pursue it. Now, do patients want patient-centered care, and what are their expectations about it? The answer is yes. And I don't know how old you are, but I remember observing and appreciating, what has been called, the Patients’ Right Movement, that was recognized by the World Health Organization in the '90s, there were actually efforts to get this going much earlier, but it just took it's time to get traction and really become something that basically changed the world in healthcare.

First of all, WHO calls it the highest available standard of care, because we're honoring confidentiality, full disclosure and transparency options, shared decision-making, mentioned again, and also, of course, non-discrimination throughout. Also, more importantly, the underlying theme of all this was the end of paternalism, the doctor-knows-best culture, they called an end to it, enough with that, this has to be about
what the patient is doing, and what the patient wants. And so we discuss and define what patient autonomy is and patients rights, which now everyone is familiar with patient rights forms that they fill out. What does it mean with the clinician-patient dialogue? It has to be more balanced, it has to have less control, from the clinician's point of view, with a fair exchange of views and ideas on both sides. And thinking about how to share power for the common purpose, which is the patient's best interest. Here's an example of another study, a meta analysis, from 10 years ago now, it was a big deal when it came out, what about the relationship between a physician's communication and patient adherence to treatment? And I wanna highlight the word adherence because we still see in some literature, the word compliance and the choice of words matters. Compliance implies that a person will listen to an expert and obey. That isn't really treating an adult as an autonomous decision-maker, is it? Adherence means I'm listening to your input, and I decide what I like about this, and I will agree to your recommendation.

There's a new thinking on this, the word is concurrence, meaning I am adding my input to this discussion, and then we will concur together, that this will be our steps forward. But to this meta analysis, here are the details on it, they conducted a literature review, taking a look at 60 years of articles that were published with the predefined keywords, of course, and they found 106 correlation studies and 21 experimental interventions that met their criteria. And their analysis, I'll just skip 40 pages of this article and bring it to the conclusion, they found a strongly positive and significant relationship. And to get a P value of 0.001, is to die for, between a patient’s adherence to recommendations and their physician’s communication skills. So what were those communications skills? Being able to engage the patient’s input that they’re eliciting and validating their concerns, inquiring about their ideas, legitimizing their expectations, taking a look at the impact of the symptoms on the quality of their life, that World Health Organization chart, not just the symptomology itself, not just the disease itself, and responding to patient clues to emotional distress by using empathetic language. So what does audiology conversation tend to look like, that's what we have to be honest about. This

continued
is just an example of work from Australia. This is from Caitlin Grenness, Barr is her maiden name, what’s the nature of communication throughout the diagnostic and management planning, in audiology consultations? They recorded 62 interactions between patients and audiologists. 60 of those patients were diagnosed with a hearing loss, and 50 of them were recommended to obtain hearing aids. It did include 26 audiologists, what I really appreciate it, again, it’s not just one or two, they’ve got a really good sample of this. This study’s been talked about so much, you’re probably already familiar with it, they took a look at the communications and analyzed them according to the diagnostic component of the appointment, or else the treatment component, and what they found, if you were looking for patient-centered communication, they didn't find it, hardly ever. The psychosocial concerns expressed by the patients weren’t addressed, again, that ignore, if you think about that left-hand column in the flowchart, they missed opportunities, almost an invitation by the patient to develop some kind of relationship, and they just glossed over that, the patients had little or no involvement in the management decisions, and most of the time the talk was about hearing aids, the recommendations for hearing aids were made to 85% of the patients, only 56% followed recommendations. Those are the outcomes that we do not want, it means that we missed something including their own reactions, and impressions, and what was important to them.

And also, in addition, alternative options were rarely discussed. Now, we’ve all been to school for so long, and we know about those alternative options, why aren’t we capitalizing on them, why aren’t we including them in our treatment plans? I don’t know the answer. Okay, thinking about that last circle in the triad of components to evidence-based practice, we have patient values. And you may already know about Shari Ebert, she’s been a contributor to Ida Institute lately, she has a blog called "Living with Hearing Loss", and what caught my eye one day, was this title, "Are Audiologists from Mars?" From her point of view as a consumer of our services, I really wanted to know what she had to say. I’m gonna skip to the blog response real quickly to help our point, if someone were to say, "To answer the question, are audiologist
from Mars, "my answer is no, "they’re from an entirely different clinic," or, excuse me, "entirely different galaxy." Further on, though, Shari, unfortunately, to my mind, felt the need to develop what she called an "Audiologist Visit Wish List," that should not exist, in my opinion. If we were really patient-centered, we would not have this on the list of focus on the person, not the product. Some people are providing written summaries now only because it’s required by insurance companies at this point. I really like to point number three, welcome us with open arms. In other words, be sensitive to the fact that it took us a really long time to make this appointment, and don’t be so cavalier about how hard this is for us.

There’s another comment here, another person wrote to say, the real question is how to get audiologists to adopt a patient-centered approach. Some do but many feel that selling hearing aids is all they need to be concerned about. This is a wake up call, if we haven’t thought about it already, we don’t want to be getting that kind of input. Another person said that her audiologist, long ago, had a questionnaire sent to her husband so that she had a chance to explain about his challenges. And that was the first time that it ever happened, and it was a big insight for her as well. That should be best practices as far as I’m concerned. And lastly, we are looking at the evidence with regard to patient-centered care, can audiologists provide patient-centered care? Yes, there’s no reason why not, but we do have to maybe change ourselves and maybe adopt some practices proposed by Donald Schon, who wrote a book called "The Reflective Practitioner". He looked at professions that were in healthcare, including nursing, not audiology, what he did was look at who achieved the pinnacle of success in these particular fields, as defined or identified by their peers, and what he’s found consistently was this practice to reflect on how today went, what did I miss, what did I completely mess up on, what could I do better, who could I do talk to you about this and have a support system in place? So again, more work in progress there. Here’s an example that we might think about in terms of reflection in practice. If we were taught to explain the audiogram to every single patient, every single time, how about if we ask ourselves why? If our first answer is it’s because we feel our supervisor looking over
our shoulder and they are telling us the patient needs to know their audiogram, it's fair to say that that's an audiologic-centric approach, we think so, but what do the patients want, that may be completely overlooked in our background. What they want is a choice and they also want some control. They may not want to hear about the audiogram, maybe they don't care, they wanna kinda cut to the chase and move on.

There's also real concerns about health literacy levels, a really highly educated person may still struggle to understand a graph like that, or there's also the concern about health literacy in general, one in three persons in the United States at the adult age, have trouble understanding what's going on in any medical appointment, for that at least that first round, so why would we use our time in that regard? Just something to reflect on, maybe talk about it at a coffee break with a peer. Palmer wrote a book on teaching and I read it when I was first became a college faculty member, then this line jumped out at me because it applies to more than just teaching, and does it apply to us, that virtually all professionals have been deformed by the myth that we serve our clients best by taking up all the space with our hard-won omniscience? Yes, our omniscience, what we know about audiology was hard-won, we scraped along and worked so hard, but that doesn't mean we have to take up all the space. And I think about it mostly is talk time with our expertise, and also our experience, but that's probably not at all consistent with patient-centeredness.

So at the end of the day, we'd wanna be asking ourselves, when we reflect on our day, how did our patients see us? Did we look like device providers only, did we look like we were the endpoint of a financial transaction, or did we look like we're part of their support system? We have a poll now, and I'll give you a heads up on the questions, if you can get yourself ready for it, to what extent is patient-centered, and there's no right or wrong answer, this is my own curiosity, I'd really like to know, to what extent is patient-centered care applied in your work setting? Is it a central tenet, a leaving living breathing principle, a formalized standard of care, is it frequently applied and informally acknowledged as a goal, is it occasionally or inconsistently applied, is it just not even
on the radar, we don't talk about it at all, or not applicable to my setting? So here's the poll. Wait a minute, where's the poll? I'm gonna back up. There we go. Thank you. We'll give it just a couple minutes, 'cause I'm already running long, I apologize. Okay, thank you, there may be some latecomers checking in, but if it's not applicable to one setting, it looks like the majority are saying, "We talk about it, "and sometimes it's even the standard of care." That's very encouraging. I'm not sure if it'll keep up going, but we'll let you take your time and get there if you need to. Thank you, Christy, I think we're going back up to the slides.

Okey-doke. Now we’re extending our thinking from the patient to the context of family. Some conversation's been going along with that for a couple three years now, I wanted to highlight an article available, included, again, with the references, but I'd be glad to send anybody anything if you're looking for it. A group of people were brought together to say let's actually develop a position statement of family-centered care, it may already be in practice, but it may also not actually be implemented, and there’s a lot of reasons why we might wanna think about it. The position statement was based on evidence, as everything else would be, is that overall, in healthcare, we find superior health outcomes associated when the family is involved and participating in the healthcare, the patient is doing better, less symptoms involved, because you’ve got that moral support there, right, you’ve got a team approach rather than being rather isolated, there’s a greater adherence to the treatment recommendations, and greater satisfaction with the services as well.

So those are all encouraging. Family-centered care benefits would also involve, if we think about moral support for hearing need adoption, encouraging your family member to use the hearing aids, and then validating the success and having someone else say, "You know, you seem to be doing better with them, "you seem to be less tired, you seem to be less edgy. "And I’m really appreciating that, "the effort that you’re putting forth." Additional RAM, as we might think about it, just that listening fatigue challenge might be reduced because it’s not as so hard to listen. Increasing the patient’s
confidence and decreasing the perception of hearing handicap when attending specifically oral rehabilitation courses. And of course, that would be Preminger's, kind of life's work there. Family involvement in audiology, also included in our literature, would be the key reason why audiologist seek, or excuse me, adults seek help to begin with, because of the family. The family can be described as experiencing what has been called a third party disability, they also are affected by the hearing loss. It's also the best predictor of hearing aids satisfaction, and differentiates from successful users of hearing aids from unsuccessful users.

Let's see, what about, I'm trying to figure out what's next here, ah, there we go, what do we think about family-centered care, and that concept, audiologists, excuse, adults with hearing loss in their families all agree that the family-centered care, according to these particular studies, family-centeredness would help develop shared understanding other issues and share responsibility for treating their mutual communication difficulties, all things you would intuitively know but it's nice to see it formalized here. And audiologists, when they've been asked by Meyer, "What do you think about family-centered care?" They think, "Well, certainly would facilitate "family member engagement and provide more education "and communication training." Is it actually applied though? The research seems to indicate that family attendance at appointment is low, less than 30%. When this first came to my attention, I thought about this and I think we've got a long way to go here. Patients may think, like getting their eyes checked, getting their ears checked, does not necessarily require a family to attend. And that's really a culture shift, isn't it, because they would go to see their dentist without family that kind of a thing, we'd have to reframe appointments, the families, for instance, may not be aware that they could attend the appointments, and when they did, they simply observed from a distance, perhaps the family efforts to engage, they're often dismissed by the audiologists, according to reports by family to say, "I might say something, but it's not really responded to, "and no one's really elaborating on my turns there "and I don't get to initiate questions." When a family member does say something, the audiologist tends to shift the conversation back to
the patient. And that seems reasonable, but it does dismiss the family input. Well, how can we affect change, how can we make evidence-based family-centered practice the standard of care? This is really more about us than families. This idea of moving from A to B is not really easy to do, so let’s think about what would be some barriers to keep us from really fully embracing and welcoming the idea of bringing families into the appointments.

First of all, we might be uncomfortable with change, not a surprise, and also we might be uncomfortable with what’s gonna happen when we do that, it’s unpredictable and that might make us worry. So we’d step out of our comfort zone, there’s no doubt about it. First of all, about change, it intrigues me to know, and this is a picture of the Eiffel Tower that was half-built, it was to celebrate the World’s Fair that was being held in Paris Eiffel when a contract to build some monument to the occasion in 1898, but when it was halfway up, and it for quite a while afterwards, Parisians hated it, they thought it was awful. This is a quote from a op ed piece, "We, the writers, painters, sculptors, architects, "and passionate devotees, "of the hitherto untouched beauty of Paris "protest with all our strength, "in the name of slighted French taste "against this useless and monstrous Eiffel Tower." Imagine that, because now, I don’t know if the video won’t work, my daughter took a picture of this when she visited, it sparkles in the middle of the night and you would be thrown in jail if you even insinuated that the Eiffel Tower is ugly, or that it should be dismantled, there’s no way, this is one of the world’s most famous icons, but it didn’t get there overnight, did it, this is what I’m getting at, that change takes time. It’s usually resisted and loathed at first, but if it’s a good change, it would be welcomed eventually.

You may be familiar with a change cycle that Prochaska had created, I’ve never really liked it, so when my co-author and I, John Greer Clark, we decided to reinvent it because it looks like you’re going into a perpetual circling and you never get out of the change problem. If we’re talking about a process of moving from A to B, these are the same stages, but we’re trying to imply there’s steps to take and the steps require a
certain amount of effort, and they may not instantly happen, but there’s the contemplation of change, preparing to change, actually taking the action to change, and then you’re either maintaining the effects of the change, or else falling kind of relapsing and deciding it was too hard, it didn’t work, or I’m gonna take a break from it and maybe try it again later. Why is change so hard? There’s 50 reasons why, we’re gonna take a couple of them. Partly because to us, it represents a loss of some kind. To the people who wrote that op ed article, that letter to the editor, rather, their loss was the vista, the horizon that they were used to seeing, and now this Eiffel Tower was inserted in the middle of it, and they didn’t like it at first. That doesn’t seem like a loss, but it is, we have to be really broad about this notion of loss. Loss aversion, trying to avoid loss, is actually been found to be a powerful mental habit. We can actually see neurological changes that struggle with the prospect of change. And because of the, actually the fact that it neurologically hurts, in other words, the parts of the brain that represent pain experiences, that’s what’s being triggered when we think about losing something, holding onto the status quo is easier. When we think about change, we become conservative.

You’ve probably heard that notion, that one bird in the hand is worth two in the bush, rather not take the change and be sure about what’s in the hand. So to avoid loss, we find ourselves becoming quite inert, that could easily explain our patients. There’s an interesting book, if you have some time, called “The Undoing Project”, talking about what does it mean to make changes, or even just to consider it? Well, some of the experiments that the authors conducted were, let’s say, I were to give you this little thought experiment, what if I gave you a choice between getting $900 right now, or a 90% chance of getting $1,000? Now, given the fact that you have zero dollars, before we started this experiment, you might think, well, I could get a really high chance of getting more money, but inevitably, they would find that people would take the $900, for sure. And we see that time and again, where they’d rather accept that small but certain gain over a mere chance of a larger gain. Even though I know that, I still get it, it doesn't help to know it necessarily. But if we think about patients who are thinking I
could stay with the status quo, I think I will, it makes a lot of sense. Loss aversion, if you google it, there's a lot of youtubes explaining it better than we have time for here, but the reactions to loss are actually more intense than the reactions of gaining something, and that's the neurological experience there. The pain of losing, let's say you win $100 then lose 80, let's say you won 100, you lost 80, you're still up 20, but it hurts more than you actually got 20, and that experience of gaining it on a bet perhaps. Where can we see it? I bet each one of us have the clothes in our closet that we probably should throw away 'cause we're never gonna wear them, but we might wanna hold on to 'em, that's loss aversion. I doubt if you hippie clothes, but some people do, I'm not saying whose. Let's see, let's think about this idea of motivation when we think about change. We probably would be assuming that this would be the process that there's three stages, perhaps, we become aware, and then arouse to the need for a problem, rather, we identify a goal in order to solve the problem, and then we change.

So it would something look like this, we arouse the problem, and then we're inspired to change in this order. Kind of get this up here, that we're thinking about it, and then we're thinking more about it, and then voila, in the spirit of France, still change happens. Now, we would be so disappointed in our daily activities with patients if we thought it was this easy, because it's absolutely not this easy. Because we think it's this easy, we often think that our first instinct is to therefore teach and explain and educate the patient and family about what they need to do. Here's the problem, here's the solution, let's go forward. And in fact, that's not how people change at all. And that we're wasting our time. I'm actually really tired of the fact that people will say, "We need to educate the public," because education doesn't change anything, does it, there's something else involved there. So for instance, I'm trying to, there we go. Lemme make sure I didn't skip a, ah, we're good. Knowledge doesn't change behavior, and this has been shown time and again, when people fail to change, it's usually not because we don't understand the problem. So if you were to think what would be some examples of that, we know that texting and driving can be extremely dangerous,
and taking your attention away for just a moment from the road could be quite a risk. And yet people do it anyway, don't they, certainly younger people, new drivers, for instance, who haven't developed a lot of awareness about these risks, and also think that they're invulnerable to change. This gentleman who's trying to break a world record in how many cigarettes he could smoke, he's just the epitome of a person who knows that smoking is dangerous and will probably kill you, and yet you do it anyway.

So there's two really clear-cut examples of knowledge, not changing behavior. So if we try to help our patients and their families know what they need to do, and work at that level, we probably won't succeed. So how do people actually change? We know that there is an arousal, an awareness of a problem, but here's the difference, one has to feel and see what that problem feels like, it has to hurt you. Before you think, "I can't stand this," "I really do need to do this change." It's not about knowledge, it's about how the emotional reaction to it is. So if we were to exploit that in a good way, a productive, positive way, to help patients understand how much hearing loss hurts their families, they might actually change their mind on what they might do, 'cause they didn't mean to hurt their families, I'm talking about social hurt, and I've heard this, I don't know how many times from spouses, it feels like my loved one doesn't love me anymore, because my loved one is not doing something about this communication problem that we're experiencing. You might remember in your neurological studies that we feel before we think, the amygdala is the gatekeeper to the frontal cortex, the frontal cortex is where knowledge is analyzed, and decisions are made, the executive center, but information does not even reach the frontal cortex, if in fact, it is an emotional, and potentially a dangerous situation.

And by that I mean any threat to our self-esteem, our self-concept, our self-awareness, we are going to panic and have that fight or flight response, we feel before we think. So let's make sure that we don't talk to the frontal cortex when people are upset and distressed. So how do we go about reducing discomfort when it comes to change, there are these key points. We know then that change means loss, and reaction is
called loss aversion. We know that knowledge doesn't change behavior, and we could call any negative emotional response could be an alarm, kind of a siren going off, to say that this status quo, the emotions about my status quo can change the behavior. In other words, I'm upset enough about what we're going through. And again, remember that 92-year-old patient I mentioned who thought everything was fine till he saw his wife's self-assessment. That was like an alarm bell in his brain, he did not know that's how she felt really, not in black and white on a piece of paper. She probably had been trying to get through to him, but now he felt upset that she was upset, and that helped him think about change. All right, moving on to our discomfort with unpredictability, we often talk about, "Should I open this can of worms, "when I bring family into the room, "I don't know what's going to happen," there's ways for us to manage that as well.

First of all, I would hark to a book called "Difficult Conversations: How to Discuss What Matters Most", it's in its 25th year, I think, in terms of wide usage, people are big fans of this book, because it applies on so many levels, and we will do so here, but they were pointing out what most people think that when a difficult conversation comes up, for instance, let's say the family is starting to get upset about what the patient's position is about hearing problems, and they're starting to become accusatory or other concerns there, becomes a difficult conversation, Stone and colleagues would suggest that our first two reactions are either to avoid this altogether and move on, or to confront it, to think that we can, somehow with our knowledge base, persuade everyone to think about it differently. But they developed the third option called a learning conversation. First of all, learn the other's perspective, "Please help me understand," but then also share our perspective, and then ultimately come up with a new story that didn't exist before, co-create another way to think about it that will solve the situation to the patient and family's satisfaction. Excuse me. We do need to keep in mind that these difficult conversations is how people feel, it's the emotional response that maybe was kind of beat out of us as a science field, but it would discourage families to realize that we didn't care, excuse me just a moment, I apologize, that, in fact, how they feel is the very core of these difficult conversations. And it may seem
efficient, therefore, to jump over the emotions, to leapfrog over 'em, as they say, and move to a problem-solving mode. But in fact, there's plenty of research to show that people still stew on the distress. I do apologize, hold on. In real world, I'd be turning the conversation over to you, and I'd ask you for your input here and give my voice a rest, but the point being that it may seem efficient, for us to not pay too much attention, or dwell on the heart of the matter, as we might call it, but in fact, it will come up time and again.

And if we can't really escape it, there's a favorite quote of mine from Mary Pipher who says, "You know what, "we really do have have to acknowledge feelings, "because if we don't, they don't disappear, they fester." And the word fester is a great one, isn't it, reminds you of things like boils and stuff, it's disgusting, and it does not go away on its own, it needs to be addressed. So if we think we can rush this process, it's actually going to be counterproductive. All right, let's think again about our comfort zone, what about reducing our discomfort with regard to predictability? First of all, we wanna strive for learning conversations rather than trying to teach people what we know, let's respond for those emotional states that patients and their families are presenting to help provide support to everybody, and also take a look in-house with our peers that we work with, or that we are in touch with online, "I am not comfortable with this unpredictable situation, "how do you all handle it?" We can't do this by ourselves, we do need support from our peers, we don't wanna think that we are the only ones out there.

There's two recommendations that came from that position paper on how to support family-centered care, they were 10, I'm going to highlight two of them, and one is to invite a family member to an appointment, which may or may not already be happening in your site. And if so, kudos, we find that, when we just asked informally, most people don't think about it. What we could say, in terms of codifying the situation and making sure that we always do, the person who does make the appointments might say something like, "So our experience, "first of all, we're delighted "to have you come to
our appointment, "and be sure to bring paperwork and all the rest of it. "But our experience is that it's very helpful "if you can bring a family or a loved one," excuse me, "a friend or a loved one along to the appointment. "And so who might that be?" So the invitation has been extended. If the patient were to ask for more information, like, "Why do I have to do that, "I don't bring a family member when I go to the dentist?" The next follow-up would be, "Well, there's a lot to discuss "and it helps to include family and friends in the process." We don't wanna talk about third party disability or anything, it's just, "Four ears are better than two, "two brains are better than one," that kind of a thing. They have the right to say no, of course, but we could always reinforce the invitation with any information that you sent in writing to confirm the appointment as well. I'd mentioned before about how do we change evidence-based patient-centered practice into a standard of care? Does the intake person consistently invite a family member?

I just recently was in a clinic where the intake person knew she was supposed to, but she just didn’t, and there was really no getting to the bottom of it. So the people who ran the practice changed the intake form that had to get completed, every single box had to be addressed, and they added this question, "Our clinic finds it helpful that you bring a family member, "who would that be?" In other words, could you tell me a name, or at least the relationship, and that box would be ticked off, and then if you get the name, you write that in. And then the next part that I appreciated from our colleagues in the site that I was at, was that they then did realize that when a student provided care to the patient, and the family member was involved, the family member was never mentioned in the clinic report. And so the person who was supervising the student said, "You're gonna get dinged on your grade, "the family member is part of this process." And the student, they were struggling. So they put on the form, that the student had to complete, the name of the family member. In other words, those are the mechanisms they put in place to make sure things happen, that's how we are more comfortable with unpredictability here.
We also wanna think about the physical environment, which may be already on your mind, and you're already taking care of it, the idea that when there's a place for family to sit, and that they're comfortable, and they do definitely feel included and not feeling like they have to sit in the back of the room. I was once supervising another university where the student had the patient in a chair and the family member wasn't along, but there was no chair and the family member just kept standing. And the student never thought to take these people out of the booth into the consult room, it was the most awkward situation. Well, she never did that again, she knew there was a problem, she didn’t know how to fix it. So how can we have an inclusive physical environment that fosters a sense that everyone can equally provide their thoughts and perspectives? I was talking about this concept to a colleague who works in the UK, and she emailed me to say, "So I had this situation recently "where I asked the patient to get the things going, '"Do you have any issues with your hearing?" And the patient said, "No, I don't think so." But then the wife, who was sitting in the corner of the room leaned really far in and said, "Yes, he does."

And the person who was taking this workshop, left it there, and I said, "Why was she in the corner, "was the chair bolted to the floor?" And she said, "The chair has just always been there." So I said, "Would you be comfortable "with moving the chair a little bit closer, "maybe to look a little bit from this to this?" And she said, "Of course," so she tried it. And what she found out, and it’s just a natural thing that you really would hope to do, is not only is the patient and the family talking in a comfortable way to the audiologist, but they’re probably gonna talk to each other more too. And they may not have ever talked to each other before about what these issues are until now because the audiologist can keep the conversation focused, and also, at the same time, stay out of it because it's not our family, but with open-ended questions and other ways to encourage them to share what it's like, they have a more honest conversation, honest experience. Just a point of pride, I was glad to say we had an extra room in our clinic, at the University of Akron, it was rather large, as you could see, on the left-hand side in the back was a lab for students and clinicians to make hearing aid modifications, but
we always had plenty of chairs, we put it in our budget to make sure they could be moved around. On the right-hand side was a demo on how you might wanna use open captioning on your TV, or how we might do teleaudiology, and all the rest of it. But all very much meant to imply that there's room for everybody, and let's just, hopefully our students will see that when they leave and think that's what we should always do, then make sure that our family members are included.

All right, there are some caveats, of course, to family-centered care as well. First of all, we know that not every family is The Brady Bunch, I don't even know who to think about, a functional family, some of them really have problems, and there's nothing we can do. We are not family counselors, and we get the sense right away, that there's a problem here that we cannot address, and so we don't. I was once working with a patient who was a female, very eager to get some help, we were moving along quite well, her husband was in attendance, not saying anything, his body language was indicating hostility. And at one point, he stood up and he said, "No wife of mine is going to wear hearing aids," and he walked out. There's nothing an audiologist can do about this, this is a marriage problem. The patient cried and she left. And what a memory that was to think. My thoughts on that gentlemen we're not positive ones, but this is something that we know when we're in over our head, and we know we need to not engage. But can we still be expected, when things are going well, otherwise, with a functional family, a family that wants to work together on this, there's gonna be a certain amount of uncertainty, and ambiguity, and complexity, but let's just know that it's going to happen and not try to avoid it, but to work with it actually.

All right, we have our next poll. Here's your heads up of questions. Two parts, actually, the first one, regarding the steps to include families in appointments, does your work setting do so, do you have procedures in place to ensure family members are invited to attend appointments? Part Two, regarding steps to include families in appointments as your work setting, ensure seating arrangements include families in the conversations. As the votes continue to come in, it does look like the majority is dedicated to at least
inviting patients, that’s really heartening. And I’d love to hear from you directly sometime about how that’s going, everyone, I think everybody, every family is gonna have its own story in terms of success. And looks like most people, if they will, of course, if they’re invited, we have to have a place for them to sit. So kudos there, we’ve got plenty of chairs for everybody there. Thank you very much. So I think we’re allowing about 10 minutes for questions, and I don’t know if there are any, so I’ll turn it over to Christy.

- [Christy] Thank you, Dr. English. That was a wonderful presentation. We’re gonna go ahead and open up the floor now for any questions or comments for Dr. English. Oh, here we have a question from Stuart. Stuart asks, we owe the families quite a bit, many of our patients are brought to us via a family member. I agree, Stuart, what do you think, Dr. English?

- Is there a question?

- [Christy] I think it was just a comment that families are a big part of our profession and how we get to that goal for our patients.

- I’m with you now. Thank you, Stuart. I am so in an agreement with you, it’s the reason why I agreed to be part of, what they called an expert panel on this. I’ve had my own family members be kind of stuck on problems that were poorly handled, because fam, excuse me, family members were not involved, and things fall through the cracks. I started off as a pediatric cardiologist, you would never move forward without family, I mean, that’s how that works. So when I shifted to adults as well, and I thought, "Where’s the family" it’s always been a bit of a concern to me. And when family does arrive, I was never really worried about what could happen, because I figured it was going to be either with good intent that we’ll navigate, or there’s a really rare, broken family that I’ll just have to make the best of and wish them well and move them forward, but I’m very clear on what I will address and not address, but only on a rare
occasion, you're reminding me of another point that I was wondering about making, rarely does a family say, "There's nobody in my life. "All my family not only have they all passed away, "but I live alone in the retirement community, "and I have not made a single friend." This really is important to know because not that we can help find friends for them, but they may also be at great risk of depression, they may actually be in grief in a deep sense, where they really don't know even how to reach out to other people as well, and then we might find ourselves leading to a conversations to ask if they could see, would they agree to a referral for a different kind of help? It might not have come up otherwise if you didn't know that they felt that they were familyless, that they were so much an island, and they had no one else in their life. Now, that may be self-imposed, we don't know, but, I think it's only happened twice in my career where people said there's nobody in my life, so.

- [Christy] Thank you, Dr. English. We have a question here from Christopher, he asks, "Do you recommend a book or article "describing the psychology of the hearing impaired?"

- For family use, or just general?

- [Christy] Let's see, I think Christopher might be referring to in general.

- Okay, thank you. 'Cause I didn’t know if you were looking for families might need to know some things. When I was in grad school, there were actually quite a few books that were in, I just absorbed all of them, and then I noticed that they started to get replaced. And I think the reason is, it's because they were to generalized and they were to pathological, they pathologically, I'm not sure how I'm gonna say it, they pathologized hearing loss, psychologically, and socially, and so on. I think it’s actually very fair to take that off the table. So to your question, there are some good counseling books that you might want to take a look at. And the reason I bring that up is because the counseling is going to mention some known challenges of living with a hearing
loss, working with a hearing loss, growing up with a hearing loss, and then what is our role accordingly? So it's not putting the person with a hearing loss out there as a specimen to investigate, or to understand under a microscope, but to say, "They're living a life "and we're now engaged in their life, "how can we be of help?" So I would encourage you to take a look at the counseling books in audiology that are available.

- [Christy] Thank you, Dr. English. We're gonna leave the floor open here just for another few moments to see if there's any comments or questions for Dr. English. We just wanna thank you, to you and Dr. to DeConde Johnson, for just being a wonderful pair for this series. It's been truly a helpful series to watch. We have one last question here from Pierre, Pierre says family-centered care has surprisingly worked well, very strongly for my work with veterans and demonstrated to me that the family-centered care is the most important and simple intuitive work on the audiologist part, and that needs to be the gold seal, nothing less. Just a comment there.

- I really appreciate the testimony, and I hope you find a way to advertise that more, because there's folks who have not, remember that stepping out of your comfort zone, they haven't tried it yet, and it may not have been imposed upon them, and they are not sure that they can do it. But if they find out from you, for instance, that it's intuitive, I love your word for that, what I have found, it's liberating, 'cause you've got someone else, at least one person, to help you and take it home and make sure that what was said was understood well, so someone else could explain it, or more importantly than the explanations is the moral support. I can share with you real quickly, let's see, we have a couple minutes, a story that I had shared with some folks about family-centered care. My first experience with my family was with my grandmother, who ultimately reached the age of 100, which is awesome, but way before that, my mother had called to say, "I need the name of an audiologist," in the town she was living in "'cause your grandmother needs new hearing aids." And I said, "Sure, let me find somebody. "What's grandma say?" "Oh, she love it, it's gonna be a big surprise." And I said, "That's not gonna work, right?" I mean, you could see this coming a mile away. But my
mother was gonna go ahead on this with or without my recommendation. So I found somebody and let them know that this may or may not work. And so they made the appointment, and yes, my grandmother’s hearing had dropped and the hearing aids were no longer helpful anymore, the old ones, so let’s get some new ones. So they came back for the follow-up appointment, and not too far along, my grandmother stands up and picks up her handbag, and she said, "We're going home. "I don't wanna do this." And so I really apologized to my friend. But my mother just was livid because she said her mother was so stubborn. When it’s your own family, you don’t know how successful you are at getting through to people. But I knew that this wasn't gonna work, and I asked my grandmother later, "So that didn’t go so well, what do you need me to know?" And she said, "I've already tried, "I've already used hearing aids for a long time. "I know how hard it is to get used to them. "I'm already struggling," and she started to list off the other health problems going on. And she said, "They're just gonna have "to work with me on this." And I knew what she meant was get closer to me, turn off the TV, that kind of stuff. So fast forward several years later, family-centered care’s on my mind, my mother calls me again, and says, "I need the name of an audiologist, "your aunt, which was her sister, needs hearing aids." And I said, "So what does she say?" And I could almost hear her, "She'll love it, it'll be a big surprise." So instead I said, "Wait till I get down there."

So I get a chance to go visit, and we’re all in the same room at the same time, and so I asked my aunt, "So my mom’s saying "that you’re struggling with your hearing, how’s it going?" She's says, "Oh, it's fine. "She always complains," she just shrugged it off. And so I said, "Well, hold on a minute, "so mom, can you tell me what you’re noticing and observing? And initially, my mother started to tick off, "When we’re driving around, I’m giving her direction, "she doesn’t hear me and we make the wrong turn," and she had other problems going on there. And she concluded with something about when they were in a bridge tournament, they were partners, but my aunt didn’t hear the bid, and then they lost the tournament. And my aunt’s still defensive. And so only because I had this insider knowledge about those two, I asked my mom, I’m thinking about
family-centered focus, "So how does it affect your life as sisters?" And that changed everything. She said, "Well, everything, "she's not hearing what I say, "so when I say something about the purple shoes," which I think is code for some long-standing joke, oh, you know, in their lifetime, "and she didn't hear it, "it broke my heart." And my aunt said, "You were talking about the purple shoes?" So she knew what it meant, she had the context, she said, "I didn't know." And suddenly, this is what mattered, right, this is what mattered was their life. And all I had to do then was sit back and let them talk about what really mattered was their memories and their history and all the silly jokes, and all the, you know, thus they didn't wanna lose that, and that's something. So I'll leave you with that anecdote, lessons learned in the field with one's own family.

- [Christy] Thank you Dr. English for sharing that story. We have one last comment from Jennifer. She just wanted to say that it's been an amazing series, and I agree with you Jennifer. Thank you again, Dr. English and to Salus University. We hope.