Patient and Family-Centered Audiology, presented in Partnership with Thieme Publishers

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- [Moderator] Hello everyone and welcome back to the classroom. We are delighted to host Dr. Louise Hickson today all the way from Australia. Dr. Hickson is the professor of Audiology and Associate Dean in the Faculty of Health and Behavioral Sciences at the University of Queensland. She is recognized internationally as a leader in patient and family-centered hearing care. She has over 250 publications including five books, 20 book chapters, and is committed to the transfer of knowledge into practice. In 2013, Professor Hickson received the International Research Award from the American Academy of Audiology. Thank you so much for joining us today, and at this time I'll hand the mic over to you.

- Thank you very much and hello everyone. I'm delighted to be here to present on this topic that is very dear to my heart and hopefully also to yours. Patient and family-centered hearing care. I have been doing research in this field for a number of years with many colleagues here at the University of Queensland in other parts of Australia. And the impetus for this particular presentation for Audiology Online today is that we have recently published a new book on this topic, patient and family-centered speech language pathology and audiology. So, today the focus is on telling you something about the new material that appears in this book and hopefully piquing your interest to have a look more closely at the book. So, without further ado, I'll move on to what the learning objectives are for today. I am hoping t hat after this course, you will gain a deeper understanding of patient and family-centered clinical practice and be able to describe the nature and benefits of that practice. I'm hoping that you'll be able to identify the needs of patients and families affected by hearing impairments. So, what is it that patients need. And I think we're probably pretty well aware of that but it's extending that to really deeply understanding what families need and how, as an audiologist, you address the needs of both the patients and the families. And finally the learning objective about meeting the needs, once you identify them, how do you meet the needs of patients and families to an approach of collaborative management planning, something where the audiologist works with the patient and with the family.

So the focus and the reason for this presentation is for you to consider how to bring true patient and family-centered care to your audiology practice. So this is the front cover of the book. You can see it there, my colleagues Carly Meyer and Nerina Scarinci and I have put this together. Carly and Nerina are both speech language pathologists, and my professional background is of course audiology although my first degree was in Bachelor of Speech Therapy as it was at the time. So we have a collective understanding, if you like, of the importance of patient and family-centered care for people with communication disorders. So, in that sense speech language pathology and audiology are very close in their understanding of patient and family-centered care. The book is brand new published just this year, very recently. And it is a small paperback, but also importantly and a new thing for me, it's an e-book. And you'll see today some of the video and materials that are in the book, and this has been very exciting to have this new medium, if you like, for a book. So, we really hope you enjoy it. Whether you of it but we have also a new way of involving contributors.

So we have contributions for some 46 colleagues around the world. They've either written short reflections in the book or produced a video or developed a case study. So there's lots of different ways people have contributed, not the typical way, if you like, of writing a chapter. But they've contributed in other ways. And we're hoping in this new medium to make the book come alive as much as possible and be as exciting as it can be for the audience. The learning is very structured around case examples, so we're really trying to make it super practical. The foreword was written by our colleague from Weill Cornell Medical College, Professor Joe Montano, who some of you may know from the US. And he's been very enthusiastic about the book. He's also one of the contributors to various sections as well as writing the foreword. It is a book principally designed for students, and it's written in that way. But we also feel that it's hopefully useful for many clinicians. And the material in it might be the sort of thing that you want to use in your clinical practice for discussion and reflection with staff. So I think it's a learning tool if you like is probably the best way to think of this book. So these are the various chapters, and the beginning is giving an outline of general principles, getting ready to be a patient and family-centered clinician, so reflecting on your own beliefs and approach to clinical work. There's a chapter on the environment, the clinical environment, and how it can be more patient and family-centered, and how your whole service delivery approach could be patient and family-centered. So some of these ideas you may well have considered, but some might be novel for you. My focus today is on chapters five and six which I led which were about identifying patient and family member needs through assessments. So once they come to the clinic, and then meeting those needs through collaborative management planning.

The final chapter is very interesting work led by my colleagues Carly and Nerina. And it's considering the cultural and linguistic diversity in patient and family-centered care which of course in our multi-cultural societies is extremely important and more of a new area, I suppose, to appear in a textbook of this kind. So, that's the chapter outline. And let's start by going back to the concepts if you like, first of all talking about patient and family-centered care which is where a lot of the discussion in this area began. And if you remember your lectures from psychology as a student, you'll remember Carl Rogers. And Carl Rogers talked about the relationship between the patient and practitioner as a key to success in any clinical encounter. It's not just what the patient brings or what the practitioner brings, but the importance of that relationship. The work of Rogers has been developed further by many clinicians and researchers, and there's a classic paper from Mead and Bower in 2000 where they describe a framework for patient-centered care and highlight the fact that the aim of it is to promote high quality holistic care where you empower the patient to be active in their health care and not a passive recipient of care. So that's an extremely important element and something to always remember that you're working alongside a patient for them to achieve what they want to actively participate in their own care. What you can see in the circles on the bottom of this slide are the four principles of patient-centered care, and you can see a couple of more recent references there. As I say there's a lot of work being done in this area, in all areas of health care. But the four principles, the first relates to the clinician, the fact that the clinician needs to operate with respect, empathy, honesty, all those characteristics that we know are so important. The second circle talks about the central role of the clinical-patient relationship, and that goes back to the original Carl Rogers idea. The third circle reminds us that the clinician needs to consider each patient as unique. Now this is quite challenging. After a while, you're working every day seeing client after client. It's easy to start to think, oh, they're all a bit the same. They've got difficulty hearing in noise, they're denying their hearing loss, that kind of thing. But our role as respectful, empathetic, honest clinicians demands that we think of each person and their own unique circumstances, think of their circumstances as unique to them which of course is how they are to them. So, that's quite a challenge I think in the rigor of a busy practice, but it is important.

And finally the clinician needs to understand the patient in a holistic biopsychosocial context. So, that is different from a biomedical context thinking about the symptoms they bring, tinnitus, vertigo, et cetera. Biopsychosocial means that you need to consider the biological, but equally you need to consider the psychosocial context in which that person lives their daily life. So that's extending our thinking beyond the medical nature of the hearing condition. So, patient and family-centered care, so abbreviated here to PCFF, is an extension of PCC. So it began with that but it's now extended out. And it's so important in many areas of health care but particularly for communication disorders because you don't have a hearing loss in isolation. Your hearing loss impacts people around you and their communication with you. So, it's particularly important for people with communication disorders. And there are three domains. And this is the conceptual framework for PFCC that is in the book. The first is the effective therapeutic relationships, so back to Rogers again, but this time extending that you need a relationship between patient, family and clinician. So, all of those. And not just mediated, not just the patient allowing the family occasionally. But really the patient has a relationship with the clinician, the family has a relationship with the clinician. And then of course patient and family have a relationship. So that is the key there at the top. And so what you need to do on the right hand side is consider the patient and family biopsychosocial needs, so it's extending that idea of considering holistically what the patient needs. It's what the whole family needs. And finally care that's provided needs to be driven by the patient and family. So, again, not just he patient and not just the family, as happens sometimes, but by the patient and family. So they are the three core concepts to do with patient and family-centered care. I just wanna say a little bit about family. In this model, PCFF, you think that the family is the unit of attention, not just the patient. But who is family? So, it's definitely beyond biological is the main point. Family is defined as two or more persons related in any way. Now it's typically biological but not only. Could be a legal or an emotional relationship. It's any individual who plays a significant role in a person's life. I'm sure you can all think of people in your lives who are not biologically related to you but who are family. So they are the people, if they're coming along to appointments, that's the family. And another time when this concept is broader is of course when you're working with people who are living in residential aged care for example where they might come along with someone who lives with them in the home or is a carer in that home. So, think of family broadly. That's very important in this context.

I just want to show you the kinds of case examples that we have in the book that we work through in the book that highlight these ideas and remind us that the complexity and the unique nature of each client, or each patient, sorry. We use the word client in Australia. So every now and then I slip back into that. So one of the case examples in the book is Emily, a 23-year-old singer in a local indie band. And she talks about the importance of singing in her life. She performs Fridays and Saturdays at local music venues, and she loves it. And financially it's important to her. It's supporting her through her studies in music. She has started to notice vocal nodules and has seen a speech pathologist about that in order to develop better vocal behaviors of course. But recently she started to notice a change in her ability to hear in the background noise of these venues that she's playing at. And she comes along with her boyfriend Hugh after having hearing assessment. The audiologist does find that Emily has a hearing loss and consistent with noise exposure, of course, one of the complicating factors of the work that she's doing. Together Emily's voice disorder and hearing loss mean that she's really struggling at something she loves at performing at these regular gigs. And it's also affecting her university studies. So, the severity of her conditions, if you like, is somewhat mild. However, the impact is starting to be enormous in her life. So, we encourage in the book for people to think about the holistic management of Emily, not just the hearing loss, not just the vocal nodules, but thinking about her and what's important to her. And you can see here some of the things that are important to her music, of course. Her boyfriend, Hugh, university, her studies, singing that she absolutely loves, and of course finances. The singing is important for her spiritually but also important to her financially so that she can do what she wants to do in life. So this is just to show you the kinds of examples that we have in the book to highlight the content that we're providing. And we hope that these add interest to the theoretical understanding of some of these concepts.

We also summarize the research evidence about patient and family-centered care. And this is a table that we have in the book that shows a summary of all the things that have been found not just in audiology and speech language pathology, about the benefits of such an approach. Now you would expect the patient level benefits. I think that's probably the main thing people think about when they think about why it's important to deliver patient and family-centered care. People can have better health, better outcomes. There are many studies in this area. For children, better behavior, improved self-efficacy or confidence in your ability to deal with any health condition, better knowledge, improved attitudes, better adherence to treatment. Now that's been found in audiology, and that's an extremely important thing because we're often recommending treatments such as hearing aids where adherence or use of the hearing aids can be quite variable. So being patient and family-centered will improve those outcomes. There are also family level outcomes. You can see there reduced anxiety and depression. So, family feel the impact of a health condition as very often, to the same extent as the patient, not always, sometimes it's milder. But they can feel it just as much. And so, in a way you're treating them as well as the patient. And you can see in that table lots of examples of how family level outcomes have been improved.

There's also been some research on clinician level outcomes. If you're a patient and family-centered practitioner, you will have improved knowledge of patient and family management plans, better communication skills, better engagement, better job satisfaction, and reduced burnout. So there have been proven benefits for the clinician. And finally improved benefits for the service. So, basically your clinic and your practice is going to do better in terms of patient level outcomes and some family outcomes and some financial outcomes for your practice if you can really embody patient and family-centered care. To highlight this I'd like to introduce this next video, or this first video, sorry. I'm going to show you a few today. And this is presented by Bettina Turnbull who's the director of Audiology and Education for Sonova in the Asia-Pacific region. She's based in Sydney, Australia. And she undertook a project within a series of clinics to implement patient and family-centered care. So she's going to talk about from the perspective of your practice. So let's watch that video together now.

- So what's the value of implementing family-centered care? I'd first like to go into a bit of definition. When we implemented family-centered care into our organization, we called it client-centered care. And client-centered care really incorporates both the person-centered care and the family-centered care principles because we saw the client as being the whole family, not just a person with a hearing impairment. So, if in this video at any time I talk about client-centered care, please take to mean both person and/or family-centered care. Secondly, I see that there's a distinction between person or family-centered counseling which refers to the technique or the way we are counseling with the clients, so the actual interaction between the clinician and the client. And we distinguish between client-centered practice. Client-centered practice really moves beyond the interaction between the clinician and the client. It incorporates an entire philosophy that the business organization is following. In this case, all aspects that affect the client such as developing new procedures, the way the room is set up, any services that are delivered, everything is taken into account from a client's perspective to begin with and are designed to benefit them the most. So, I think this in itself is of great value because it's difficult to implement something when really only the coalface are doing it and not supported from behind. So there could be an incongruency for example in a clinician trying to deliver a really client or family-centered approach. But if the back end isn't supporting that, that can become very difficult. So, on a more practical level, the value in implementing a person or family-centered care to me is three-fold. First of all, what we're always after is that our client's benefit. We're looking for the best benefit for them and for their families. So, the way we can achieve this through family-centered care is really that we are looking for a shared way in solving problems and we are able to explore the difficulties that they each have from different perspectives and this allows a deeper understanding in empathy for each other's perspectives and ultimately makes for a holistic way of tackling any problems at hand. Second of all, the organization benefits we found that some clinicians were really way more engaged in this way once they've kind of really got it and started practicing this way. They were much more engaged. And this really rubbed off on the client. So, ultimately what you're really hoping for is that your clients are so happy that they'd go and tell their friends and we have a word of mouth happening. So, thirdly there's the personal perspective. I think if you're really practicing in a client-centered way, it starts to change the way you think. And I found personally that it did affect the way I deal or I view my relationships and also the way I interact with my colleagues, with my friends, and my family. And to me I feel you establish, you could have richer relationships.

- Thanks very much for that, Bettina. So, just to summarize here some of the literature from my group and the work of others about the benefits of PFCC, patient and family-centered care, specifically for audiologic rehabilitation. So we've been, as I said, doing research in this space for a number of years. And so if you think about your audiology clients, we have clearly shown that you will get improved outcomes for clients. That encompasses a number of dimensions. The first is that people with hearing impairment have family support are more likely to seek help. So I'm sure you know that from your own experience, but we've definitely seen that in our research. Families also help with rehabilitation decisions, so they are the reason often that someone comes to the audiology clinic. Then when they're there, if they're involved in care, they can help with those decisions. And finally, people with hearing impairment who have family support are more successful with using hearing aids. So that goes back to that adherence to treatment idea. In terms of families themselves and the benefits they get, there's a concept called third party disability where a family member does not have the health condition but they experience it, and this has been shown in hearing impairment. And you can imagine that lots of communication breakdowns, not going out as much because your family member has a hearing loss. So the family can experience third party disability even though they don't have the disability. And if they're involved in treatment, they will get improved outcomes or reductions in that disability. So, it's another dimension.

And finally there's some work done by Gurjit Singh and Stefan Launer looking at the outcomes for business if family members attend appointments. And they showed in their research that people with hearing impairment were statistically much more likely to obtain hearing aids when families attended the appointments. So, you can see there are benefits. If I haven't convinced you already, there are benefits across the number of domains of patient and family-centered care. We've then gone on and done some research about whether or not it happens in audiological practice in Australia. And look, its uptake is limited. And we'll talk about there are many reasons possibly for this. But just to say that families seem to be attending audiology appointments, in Australia at least, only 20, 30% of the time. So it's pretty hard for them to be involved if they're not there. So, that's somewhat limited and it'd be important for you to think about your own practices and how often family attend and how often they come along. This is in the adult context. When they do come, we observe that family members were not typically invited to join the conversation. They were often sitting towards the back of the room and not invited in. If they were at least sitting at the table sitting together, they were often not given an opportunity to speak. The focus was almost entirely on the patient. And so what would happen then if the family wanted to be involved, they would sort of butt in. So the audiologist would ask a question to the patient and the family would answer that kind of thing. And they would self-initiate expansions of the person with hearing loss's turn. So the person with hearing loss might say something like, "Oh, I don't have any problems," and the family member would interrupt and say, "Oh yes you do, you have a lot." So, they weren't invited in to the conversation. So that's not patient and family-centered care. The audiologist really focused on the patient, person with hearing loss almost exclusively. So, there were some limitations there. One of the things, one of the barriers and the reasons that we think that might happen is because clinicians have a view that that they have to focus on the patient, that it's not right to talk to the family and maybe they're breaking some boundaries. So what I'll show you here is Gurjit Singh talking about some research that he's undertaken about patient and family preferences for this kind of care. So let's play that video now.

- My name is Gurjeit Singh and I'm a senior research audiologist at Phonak Canada. I've been working at the company for seven years, and much of my research is involved in looking at patient and family-centered care and the relative benefits and outcomes associated with the implementation of this modern approach to health care. Patient and family-centered care, the three components of the model described in the book are effective clinician-patient-family relationship triad, patient and family-driven care, consideration of patient and family biopsychosocial needs, preferences and context. We've conducted one study in the past that looked at the Canadian context specifically. Our specific aim within that study was to look at attitudes towards the inclusion of family members to audiology appointments. And in that study we asked it from two different perspectives. From the first perspective we asked individuals with hearing loss how willing or how willing they were to have their family or significant other participate in audiology appointments. From the second perspective, we asked individuals that knew someone that has a hearing loss, how willing would you be to participate in an audiology appointment with that person that has a hearing loss. So we're getting it kind of from the patient's perspective and from the significant other's perspective as well. We had 70 individuals that were hearing impaired. Your average

age was 68 years of age. So that's very in line with the age of first time patients to audiology appointments. And we also had 112 and significant others within the study, their mean age, they were a little bit younger, 52.1 years of age. And we asked willingness to participate in audiology appointments in a few different contexts. And the take home message that we had from the study is that pretty consistently and broadly there was a lot of endorsement for the participation of significant others from the perspective of patients, and there was high willingness to participate in audiology from the perspective of the significant other. If we collapse all the data and look at the general trend, I think the takeaway that we had was about nine out of 10 individuals were willing to have participate or to have their significant others participate or to participate if they knew someone that has a hearing loss within to a tandem audiology appointment. So we have brought endorsement. Naturally there was that one that indicated that they were a little bit more lukewarm about having their family member participate in an audiology appointment or the family member indicated that they were less willing to participate in the appointment of someone that they knew with hearing loss. So naturally we need to be attuned to the needs of the specific individual to respect their wishes.

- So I hope that convinces you to some extent that patients and families are willing to engage in this kind of care. Certainly in Australia we've also run focus groups with people with hearing loss and their families and had similar results to what Gurjit just described then. So, I just wanted to put up this idea as well. This was is about thinking about the physical environment in which you work and whether it is welcoming to patients and families. So what you can see here are on the top two slides, two pictures, on the left-hand side is a very bare looking clinic room, speech language pathology. And on the right-hand side, a patient and family-centered care clinical room, much more welcoming to patients and to families. And that's embodied in the nature of the seating arrangements, the personal artifacts that are there. So, you can see a difference. Audiology is a bit more challenging. We have a lot medical equipments. So on the bottom there you can see before and after photos of a clinical setting that has changed from being less patient and family-centered and more biomedical in its construct, to more patient and family-centered. And this has come about again by the inclusion of sort of personal artifacts and by the images that are put around. So these are cards, cards on the back wall and personal pictures. So these things just can make an environment more welcoming. And it would be interesting if you wanted to photograph your own clinic environments and see them from the perspective of patients and families. Consider the physical setup. Where do families sit when they come in? It's the balance between the clinician to patient and the family. Is it equal? 'Cause that sends a positive empowering message. So think about your physical environment and how that might be more patient and family-centered. This is an example of an office that's very personalized and patient and family-centered. And this is Professor Joseph Montano's office in New York. And he always sits at this table with the patient and the family, and you can see a round table, no equipment on it at all. He listens to people, he records the information afterwards, in the file and on the computer.

And you can see there he's interested in music and he has a number of album covers up on the wall. So this is a source of discussion with his patients. He's revealing something about himself, and that encourages them to likewise disclose things about themselves. So, it's just to say it's something you might want to reflect on how your clinical environment looks to your patients and to their families. Another thing to consider is in your clinic is the material that you provide to patients and families. We've done a lot of work in my own research looking at the kinds of instructions that are given out, for example for hearing aids. And if you look on this slide, on the left-hand side are the original instructions for a hearing aid. And then how they were modified is on the right-hand side. So, I think we all know that there are problems with hearing aid instructions. Yet very often we continue to just hand them out. That's not considering your needs of your patient and of the family. Unfortunately it's something that you might have to do if the hearing aid companies don't do it for you. But you could look at all your materials and think, how is that experienced by the patient and by the family. Is it meaningful for them? You can ask them. You can see what they make of it. So, instead of us just designing things or providing things without considering that, we need to co-design, ask patients and families what it is that they want. So that's another example of how you might consider your own clinic and whether it's patient and family-centered. So more ideas here on list. We've been doing a lot of work at the moment trying to implement these concepts of patient and family-centered care. So, this is where a number of these ideas have come up. I won't go through each one line by line. But just to say that patient and family-centered care is a whole workplace endeavor. Think about your clinic and how you should, your administrative staff need to understand that families aren't to be kept in the waiting room. They are to be invited in. When phone calls are made, you can ask, "Who's coming along with you?" So, we've been doing education in some of our clinics with the reception staff and with the clinical staff, but about making the practice more inclusive. Having the chairs that people need, for family to come to join the appointment, giving patients and families self-report questionnaires. Let's say there's some kind of questionnaire that you give out in the waiting room to patients. If a family member is there, what can you give them? That again begins the encounter with a more equal approach. You can involve family in all your practices.

So just think about how that might happen. I'll just show you this example. We're working with a clinic that uses a questionnaire always for the patients who come in. So they sit in the waiting room and they fill out this survey with their, rating their communication ability, their readiness for change, and the difficulties that they have in everyday life with communication. So that's standard practice for the patients. When we talk to them and they reflected on how to involve families, they realize that they could give such a survey of a similar kind to the family member who comes along which they've called a communication partner survey. And you can see there that it asks on the first page the same kinds of questions that you might ask a person with hearing loss. And on the second page, it uses some questions from a survey that we developed about third party disability. So the first question there is thinking about the person with hearing loss. Because of my communication partner's hearing difficulties, I have to repeat myself. And then they score whether or not that's a problem for them. So this is setting up the appointment from the very beginning to include the family. So it might be something that you would want to consider. Now, let's get to thinking about a case history and how that might be more patient and family-centered. First thing is that point I just made about if you use self-report questionnaires. Use them for both the patient and the family before the appointment. You might send those out or you might give them in the waiting room. But use them for both. Then, when you're beginning the case history, you're thinking how to engage families so they don't interrupt, if you like, is the way to think of it. And this is what we've been doing and it's working really well. So the audiologist can say to the patient, "first I'm going to find out about "your hearing and communication, "and then I would like to find out "what your family's view is. "Is that okay with you?"

So this is a very simple prompt. It reminds you and reminds the patient and the reminds the family that everyone will get a turn. So you do start with the person with hearing loss. But you then let the family know they will get a turn. If you do that, two things happen by using this statement. You're asking the permission of the person with hearing loss to talk to the family, and you're letting the family know that they will get a turn. This works really well. Please have a go at it and see what you think. Then after you do listen to the patient and you find out why they've come along, et cetera. These are some example questions for family. You could just simply say, "Tell me how you "see things from your perspective." They won't go over the whole history again, they don't. They focus in on what they see are similarities and differences. So it doesn't add a lot of extra time. It just includes them and gives them a chance to give their perspective. Tell me how you see things. How does this affect you? And how does it affect the person with the hearing loss? You can also, in a patient and family-centered practice which I'm sure you do, observe the communication that occurs between the patient and the family and make note of that. See if they're using strategies while in the appointment to communicate with each other. So, look at that dynamic and include it in your case history. At the end when you're summarizing what everyone has told you, summarize perspectives of both patient and family noting similarities and differences. And of course finish by asking patients and families if there's anything else they want to tell you and if they have any questions. So that's some guidelines for case history taking. Now this next slide is from Gerard William. Gerard is studying his PhD at the University of Melbourne. He's also an audiologist. And he has a hearing impairment. So, this is his perspective on working with patients and families with hearing loss. Let's play that video now.

- So, I believe that my own hearing impairment does give me an insight into understanding how important patient-centered care is and how it might look like from a client's perspective. My opinion is that person-centered care is extremely valuable to actually make a difference in the lives of our clients. So let me explain. I believe that is common experience for most of us that we're probably not likely to accept and follow someone else's advice unless it is relevant and beneficial for us. So to find out what is beneficial and relevant to the client requires good questions and even better listening. So, not coming in with our preconceived notions and trying to get them to conform to our views. Once we begin to understand our client's experiences, which can be difficult to obtain in detail, because most of us don't think about hearing in that kind of specific detail. Our approach then becomes more personalized one to the person we are listening to which then makes it relevant to that client. So this will lead into a more effective partnership, more trust between the client and the clinician to achieve whatever goals, communication or otherwise that the client has. And this will, in turn, positively affect those in the client's social circle. A good principle I try to come back to and apply in every clinical encounter is that people need to know how much I care before they care how much I know. So, I try to begin at a place that recognizes values, however the client is thinking or feeling about the hearing loss and not from what I think I know about how things should be, and then just journey with them from that starting point.

- Thank you, Gerard, for that unique perspective. So, to the management plan, okay? So you've taken a case history and you're considering with patients and families what to do next. And there are three things to consider in this space. There's collaborative goal setting, setting goals together with patients and families, sharing the decision making with patients and families, and measuring outcomes for patients and families. So that's just quickly, the three core elements of this chapter of the book around management planning. And I'll give some examples from audiology of each of those areas. So, in terms of collaborative goal setting, many of you may already use a collaborative goal setting approach, and this is the COSI, the Client-oriented Scale of Improvement, where you set goals for the patient. And you consider specifically what are their needs, what do they want to achieve with the rehabilitation. And then at the end you can measure the degree of change and the final ability, it can be an outcome measure as well. But mainly the most important thing is asking people for the goals they'd like to achieve and then prioritizing which is most important. So you can extend that idea to be goal setting for patients and families together.

So this is the Goal Partnership for Sharing, GPS, which is previously been published by Jill Preminger and Christopher Lind in collaboration with the IDA Institute. And we created a slightly streamlined version after having some clinical experience of using this tool. And so it's like the COSI, right? But it's combining the views of the person with hearing impairment and the communication partner. And there you can see the questions. So, it begins by saying I'd like to get both of your perspectives on the impact hearing loss has on your communication. And so you ask both when, where do you experience difficulties? You then say, you talk through with each situation whether it's a problem for both and whether they'd like to work on both. So you end up with just three or four goals if you like. But they're goals for both. Now, this is really a stretch idea because goal setting is predominantly done now if it's done with the person with hearing loss. But if you have a couple of family and person, patient with hearing loss working together, this can be a really excellent way of them in everyday life working together to achieve the outcomes that are gonna benefit both of them. So, please try this. Please have a go with it and see how it works for you. Of course we always welcome feedback. So, we have some experience with it, but we would really appreciate others using this and letting us know how it works for them. So just to then move on to shared decision making. Shared decision making is very important for empowering people to adhere to treatment and to be more successful. And to bring that home in another area of health care, this is a really excellent talk by Victor Montoro, Montori, sorry. He talks about shared decision making. So let's watch that video now as well.

- Shared decision making, to be very conceptual, is essentially a fancy word to describe a conversation. And it is a conversation between at least two parties. One party is the clinician, so initially considered a source of expertise about the decision. And the other part is the patient, traditionally considered the subject as a decision, the victim of the decision, if I may. This gets redesigned such that now the patient becomes an expert in their own life. Patients will tell you, "I don't like to take pills. "I'm not very good at taking pills." or, "When I take pills, my body doesn't like them, "and so I get a lot of side effect." They have expertise. I talked to my neighbor and my neighbor has had this, they have knowledge that they have. It could be correct or incorrect but it's knowledge that they have and they bring in. So instead of ignoring it, it is honoring it, and it's bringing in to a conversation where they can share that, the clinicians can share their bit. And then they engage in a second phase after sharing that information where they deliberate, they consider the options and they sort of consider the pros and cons of each of the options. Pros and cons are considered in the context of the patient and in relation to what patient value and pursuit. And from that process, the option set narrows down to perhaps the next best thing we can do together. One of the ways of describing this is how I experienced when I was a small child and my grandfather was sick. And we were all in the hospital with the adults pacing around a set of closed doors. Some of them were smoking, at the time they were smoking in the hospital, pacing and pacing and waiting. And then the doors will swing open and three or four clinicians will come out with their white coats and basically inform us, "We've made a decision. "We're going to operate," all right? So, the process of information sharing with the family about the options, if it existed was the minimal requirement for essentially informed consent, right? In terms of deliberation, it all happened behind closed doors among the doctors. If you think of a single doctor, it will all happen in the doctor's head with no access, the patient will have no access to that process and to understand what were the issues that were giving greater weight, and what were relations that were giving less weight. No input at all. In our study which now includes several thousand of instances of shared decision making use. What we've identified is that on average, shared decision making interventions extend the consultation by about 10% of its duration. So for a consultation primary care of say 20 minutes, it is a two to three minute extension. Anything that enhances transparency and accountability in health care can begin to reduce the corruption of health care. Shared decision making is one strategy in which we make the options available clear in which we empower the patients to consider those options and to express their goals. I think clinicians have a moral obligation to actually do everything they can to provide that level of transparency to a decision making process and to feel that they are accountable with patients for those outcomes. If you're a young health professional and you want to participate in a patient revolution, you will see this system as it is and you will be an agent of change. Sure, decision making is one of the ways in which you manifest that spirit there or that commitment to a patient revolution.

- Wonderful. I love hearing him talk about the patient revolution. So, just to say more now about shared decision making in audiology. One way to facilitate shared decision making is to use a decision aid. And this gives some structure around the options that you might be presenting to someone. So, you can talk about what are your options, hearing aids, communication programs, assistive devices. So this is a decision aid that we've used in Australia. And they're very simple. You use simple text. You don't give a lot of detail because you're talking as well at the same time. But it's just to remind you of the key things you need to say. So what are the options? What's involved for the person with hearing loss? What's involved for the family? And then the person can tick the options they wanna know more about or options they'd like to think about before they make a decision. So, this is an example of a decision aid that helps to facilitate shared decision making 'cause it's including everyone and giving open transparent information. So we find these really useful. You can also, if the family are not there, the patient can take the decision as just a printed sheet of paper, they can take it home with them and discuss it with family so it's another way to engage family. So, the front page presents all the options. Then if the person says, "Oh, I just wanna know "about hearing aids. "I'm thinking about hearing aids." Then you can have additional material that's just another simple page again that facilitates discussion and can be taken home by the patient that gives more detail about the particular option that they want to know more about. But decision making literature would say that it is important to give options including an option of not taking any action. That's an option that should always be given. So, give options including not doing anything. And then present a little bit more detail about the options people would like to know more about.

So, it's another thing that you could consider to make your practice patient and family-centered and facilitate shared decision making. In the book, we have a number of expert contributors who talk about how they've used decision aids in their clinical practice, and these are some of their top tips. As you can see from the decision aid that I presented already, the material on them is quite simple, and you're just really being open and transparent about what the choices are. And they recommend that with that, once you present an option such as hearing aids, you don't quickly go in to a lot of detail. Rather you start with an open question. "Have you thought about hearing aids?" What do you think of them? To get people's preferences and views about that, that can be very telling. So try to resist going into so much detail before you know what their thoughts are. I mean it may be that they've heard that hearing aids are great, that they have friends who use them. So really you don't have to give the same level as detail as you might for someone who says, "I'm not sure. "I'm not sure what they look like," that kind of thing. But if you ask an open question, you can address what their needs and concerns are. You should say explicitly to your patients that you're working alongside them to make the best choices together. You can expand that to include family. You're working alongside patient and their family to make the best choices. It is true that not all patients want to be involved in the same way in making decisions. But it's offering that option. And if they say, "Oh no, you decide." That's fine, 'cause they've handed that to you. So, remember each patient is unique including their approach to making decisions. Finally it's recommended that decision aids alone, although very useful, don't guarantee that it's shared decision making. They just enable a conversation. It's up to you to make the most of them and to make shared decision making a reality. It's wonderful when it works and it's a great thing to strive for. Finally, the third suggestion in this collaborative management planning section is about measuring outcomes for patients and families. So, I'm sure you already measure outcomes for people with hearing loss. And you can use the COSI for that and many other things. What you may not do is measure outcomes for the family.

And again it's the same as you're taking case history at the beginning and you take that information from the patient and the family. At the end you can measure the outcomes by patient and families. You could simply use the COSI in which you can ask the patient and the family for how well a goal has been achieved, or you could consider using the significant other's scale for hearing disability which we've developed here at the University of Queensland. And there's some example questions, okay? And you could've measured this beforehand. Remember it was on the questionnaire when at the case history. And you could measure it afterwards and see what improvements are observed. We have done that and we have found with hearing aid fitting for example, statistically significant improvements for the family as well as for the patient with hearing loss. And that is very compelling for both because often it shows you're addressing the needs of both and it shows how really beneficial your treatment has been. So, to conclude, I hope that I've presented these main ideas of patient and family-centered care and the fact that it has benefits for everyone, for the patients, the families, for you the clinicians, and for the clinics. There are many ways to make PFCC a reality. I've given you lots of ideas I hope. The best thing would be if you could consider developing your own plan, cherry picking from what I've said and from what's in the book, what would you do? How could you make a difference? My only other words of advice is that from little things big things grow. You can't start big. You've gotta start by taking small steps. And from there your practice will really grow to be patient and family-centered. We have many people to thank and acknowledge for all of our work on PFCC. Great support from my own university, the IDA Institute, the Oticon Foundation, Phonak, Sonova, and of course a research funder here in Australia, the Hearing Cooperative Research Center. I have greatly enjoyed talking to you. I want to thank my colleagues at Audiology Online for helping me get this presentation together. And I wish you all the best for patient and family-centered hearing care in your future. Thank you.