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## Discourse Intervention in Aphasia: Renegotiating Identity Post-Stroke

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- [Amy] All right, once again everybody, welcome to our event today, Discourse Intervention in Aphasia: Renegotiating Identity Post-stroke. Our presenter today is Dr. Tricia Santos. She is an adjunct assistant professor at the School for Behavioral and Brain Sciences at the University of Texas at Dallas. She has over 20 years of clinical experience and five years of teaching in clinical supervision at the undergraduate and graduate level. Her primary research interests include discourse in healthy aging and adult neurogenic populations, adult dysphasia, health education and health literacy in the elderly and in stroke patients and therapy considerations for bilingual, bi-cultural adult populations. She also works in various medical settings as a per diem SLP. Dr. Santos has coauthored journal articles and a book chapter as well as presented on topics presented to discourse in healthy aging and Aphasia. So we're very pleased to have her here with us today. Tricia, I'm going to turn over the mic to you. Go ahead

- [Tricia] Thank you very much, Amy. Good afternoon everyone. Welcome to today's lecture on Discourse Intervention in Aphasia: Renegotiating Identity Post-stroke. In my first lecture on Discourse Intervention in Aphasia, I covered what discourse was and how it can be incorporated in Aphasia rehabilitation. For today, we will be highlighting the role of discourse in renegotiating identity post-stroke. We do have a couple of learning objectives for this afternoon. First we will be explaining the concept of loss in identity in relation to Aphasia, then we will also identify at least one essential factor in renegotiating identity post-stroke. We will also describe at least one discourse strategy that can be used to facilitate renegotiating identity post-stroke. So what happens when a person has a stroke? There is initial surprise and suspense from carrying out a daily routine and then suddenly this is halted by having a stroke and this changes everything. This is followed by the hard work, which we do during initial rehabilitation and then they're discharged to home. And there're psychosocial and practical adjustments in daily life and later on we deal with the longer term effects, which are

minimizing the effects on stroke on life and trying to get an individual sense of self. In addressing identity in therapy, Kagan and Simmons-Mackie have stressed the importance of beginning therapy with the end in mind. And so the choice of the Aphasia assessment and intervention strategies must be directly related or influenced by outcome goals, which are related to life participation in its broadest sense. So here we're not looking only at impairment in the disease process. We're also looking at trying to identify the barriers and trying to increase access and participation in health care.

Then we're moving on to choosing personally relevant goals, the relationships and the rules. And then we're trying to maximize satisfaction and quality of life. So say for example, you have an individual has a word retrieval deficit. His barrier would be frustration with word retrieval. Perhaps access could be writing or gestures in order to supplement these verbalizations. We can use relevant contexts such as if he enjoys cooking or baking, then we can maximize it to quality of life, such as maybe coming up with a recipe book for the grandchildren. Another important factor with beginning with the end in mind is that we're also looking at several important principles. So the first is the life participation approach to Aphasia. and we covered this in the first lecture wherein, we're trying to offer intensive and individualized Aphasia therapy, which has a meaningful impact on communication in life. So this means looking at emotional well-being.

Looking at the person's life activities or their social connections and looking at how satisfying these are to the person. We're also investigating the framework for outcome measurement wherein we're tryna make services available at all stages of Aphasia, with the primary goal of enhancing life participation. So we have the concept of living with Aphasia. How does this relate to a person's identity? Or their language impairment? Or their communication environment and how do they translate this into participating in various life situations? Going back to the concept of beginning therapy with the end in

mind, several studies have looked at salient features which are essential to individuals who have lived with Aphasia successfully. They had looked at biographies of individuals based on personal interviews with the patients as well as their caregivers and they're finding that having meaningful social relationships and support is essential. It takes a village to support an individual with Aphasia. Another important factor is having a positive way of life and perceiving improvement.

So striving for positivity and perceived improvement, we can do this early on in therapy when we acknowledge the improvements during recovery as well as repeatedly across time. We can provide the person with hope and self confidence and positive reinforcement to continually achieve their goals. Actively moving forward is another salient feature. So they tend to have an action and they try to set new goals, life goals so that they can participate in various activities. And in a sense, they are also trying to take responsibility for their own continued communication improvement. Also, meaningful activities is highly important as well. It's a good important salient feature. Dr.Holland had one once mentioned how meaningful activities can vary from one person to another. For example, one's love for reading daily. This can be turned into returning back to reading books which are pleasurable for the individual. Or say for example, we have a gentleman who has an active life and is engaged in golf, volunteering and seeing his friends. Then maybe this is where we want to transition their Aphasia rehab.

But the important factor in all of this is renegotiating self identity. And so in the next couple of slides, we're gonna be trying to define what identity is. So identity is a composite of rules, values and beliefs acquired and maintained via social interaction. So it's one sense of self, who we are, how we perceive ourself, our actions and our thoughts and how we interact with other individuals as well. The human language is also the mediating tool through which we express and construct our own identities as well. Now what happens when an individual has stroke? There're immediate reactions.

So they say that it's similar to a period of bereavement wherein the individual tries to negotiate a new understanding of the world and others as well. There's also crisis, a fear, anxiety, frustration and depression, which is not only expressed by the person with Aphasia but by their caregivers as well. But the most profound impact of Aphasia is probably the social dysfunction in life because here, the individual alters rules and relationships. So there's a loss of social and occupational identity. Social identity, the impact of Aphasia on friendships and social support, especially one's partner or occupational identity.

What happens if a gentleman was working full time in a professional capacity and then is now unable to return to his previous occupation? One gentleman I worked with had described his experience as follows. "I had always tried to compare myself before and after. "How I was so articulate, more spontaneous, more expressive, "how I kept on thinking that people around me noticed it, "but we were just polite to tell me. "It caused me to change jobs "as I thought I needed a new environment." We're also dealing with decreased roles, a limited communicative support system and limited communicative opportunities and there's also social isolation. So say for example, a woman who used to be very friendly and talkative prior to her stroke, now she has Aphasia. It makes it harder for her to relate to the people. This results in withdrawing from social events like avoiding to introduce oneself. Also would decrease roles, we have shifts in the balance of responsibilities as well.

So I'd like to share this quote from Hinckley that was cited by her when she says, "Society often writes off stroke victims "because they're not who they once were. "As a result, stroke victims write themselves off "for the same reason. "They're not the same person they once were. "Worse they don't know how to get that person back. "The painful reality is that "they will never get that same person back, "but often over time a better person will emerge." So I have encountered patients who ask me, what am I good for? There're difficulties in accepting changes, however, slight they may be

because the person with Aphasia would like their old self back. And so this emphasizes the importance of why we need to address identity in Aphasia because identity is a key component to improving quality of life. We get an insider perspective because living with a communication disorder is a highly subjective experience. The insider perspective is critical to meaningful intervention in Aphasia. We also learned an acceptance. And we try to encourage them to have an acceptance of new image of their self post-stroke.

So they need to rebuild one sense of self and, therefore, Aphasia therapy should focus on promoting a positive social identity. So the challenge here is trying to have our persons with Aphasia trying to make sense of life now and then finding empowerment. So our outcome assessment must capture the whole spectrum. Not only at the end of the individual deficits, but by how this translates to life participation as well. So for our stroke survivors, we're dealing with healing, regaining function, reforming and reclaiming their lives and for the families members as well, they're trying to help these stroke survivors, trying to adjust to new family roles and trying to reclaim their own lives as well. In the next slide, I like this model. This was a compilation of several articles. But basically what are the essential considerations in approaches to Aphasia? And this is the backbone of the talk for this afternoon. It's important to highlight identity. Looking at the patient's previous interests and their own perspective on Aphasia.

And then it's also essential to look at the social network, the support of the spouse or the partner, their relationships with friends and different social environments. But we're also trying to do a co-construction of competence. So building communicative competence in self-esteem and looking at experiences in a new and adaptive ways. And in many ways, I feel that discourse is the connective tissue that can unite all these essential considerations when we're looking at Aphasia rehabilitation. And so now we're looking at discourse and identity. So discourse is the core of renegotiating patient identity. There's a healing power involved when persons with Aphasia are able

to connect others via stories and conversation. We also gain personal and social insights. How are they adjusting to their Aphasia? How do they interact with others as well? It's important for us to know who our patients are. In knowing them, we are able to create meaningful social environments that will validate their identity. So knowing who and what they are prior to the stroke, what are their hobbies and activities are? Here I bring up the live cards, which I mentioned in my first lecture.

We're also trying to understand their social networks and try to help them discover who they are now post-stroke. And so for this afternoon, we will be covering narrative, procedural and conversational discourse. In the past we have covered narrative and conversational discourse. For today I will be spending a little more time on procedural discourse. Looking at past studies done and how it can be incorporated into Aphasia rehabilitation. But let's begin with narrative discourse. And here in this model, we can use narrative discourse in order to highlight our person with Aphasia identity. So a brief overview, narratives are simply telling stories. There's typically a beginning, a middle and an end. There's a main character involved and a chronological sequence of events, but not only just the telling of the story, there's also an evaluation of events, which is via emotions or judgements. Narrative discourse is very important in identity because we are continually trying to create our life story.

And narratives allow us to make meaning of experiences and to create or maintain our identity. So we're structuring our experiences and organizing events in our life and in the process, stories, personal stories, help us understand the events that happen in our life. Now how does this relate to a person who's had a stroke? A lot of literature has documented the healing power of stories. Stroke can lead to disruption in activities of daily life and it can affect our expectations for ourselves. When they tell their stroke story, individuals are able to integrate disruptions into the life story. So they try to make meaning of their disability and their life events. And then they're able to cope with the impairment and understand its impact on their identity and life goals as well. Because

they're trying to integrate subjective truth, interpretations, emotional evaluations and the purpose and the meaning of what happened to them. Through stories, they're also able to reestablish a more positive sense of self and to develop an optimal identity. So for quality of life purposes, a person with Aphasia gains a new appreciation. What went wrong? What is right? What are useful changes that they may use? The person with Aphasia also reconstructs a new identity within a social network. So there's a positive impact on recovery as well as psychosocial adjustment. It's also important for us to note that there's a social component to narrative discourse. Stories are influenced by their environment and we are constantly trying to, let me move back one slide. Okay.

And we are all constantly trying to be co-constructors of identity because we become an active listener. And it also helps us to have a relationship between speaker and listener. So you're listening with a human ear versus a linguistic ear. And there're also valuable sources of information that we can get such as priorities, cultural values and in the next slide, when a person tells their story, then they're also listening to what they're talking about. So in a sense, while they're telling their story, they're able to derive meaning and they're able to portray who they are in the story by just listening to themselves as well. And as I mentioned earlier, we are co-constructors. When we listen to their story actively, we co-construct these interactions so that we can create more authentic relationship to produce significant change.

So where do we begin? There're several areas that we can tap when we're working with individuals with Aphasia. So as I mentioned in my previous lecture, we can tap memorable experiences, frightening stories or the stroke story, which is one of my favorites. We can also use the contextual inventory of key life activities prior to the onset of Aphasia. So this was basically looking at what were very important communication contexts of the patient and then using this as a point of reference for intervention. Another area we could look at or we could tap, are the Ericson stages of psychosocial development. So individuals between 20, they're 20s to 40s, it's a stage



of intimacy versus isolation. So this is more of sharing life experiences with others once they've developed their identity. Or because there're generativity versus stagnation if the client is within between the ages of 40s to 60s, they're trying to find life's work and trying to contribute to the development of others such as volunteering, mentoring, raising children or contributing positively to society. Individuals who are older than 60 tend to look at integrity versus despair. So they are more on the reflective side, looking back on life. Another area we can tap is the reminiscence bump.

So the reminiscence bump is, these are events from late adolescence to early adulthood. And it's typically the first job, the first marriage, the first child, the first pet. In memory studies, cognitive psychologists have shown how these memories are more frequently rehearsed in the define identity and they're better remembered later in life. So these sailing memories are accurate and tend to remain stable over time. In tapping narrative discourse, it's very important for us to understand that we are an ongoing narrative. Life is an ongoing narrative. We reconstruct the past and then imagine the future. When we're working with our patients with Aphasia, we're looking at who they were before, who they are now and who they will be. It's also essential for us to discuss who I am with Aphasia, which is very critical to living successfully in the long term because this gives our clients an insight on what happened to them, why they believed it happened to them and what they have done to address difficulties that they've experienced.

So the next couple of slides are sample narratives and I wanted us to take a look at them and try to identify where identity can be revealed in these stories. So I'm gonna give you a minute to try to read through this. I was sitting in my chair, we were watching the news and all of a sudden I couldn't speak. All I could do was just, and that was about it. And finally I got my sister-in-law to get some coke and I drank coke and it, my speech came back. Almost immediately with a drink of coke. Then my daughter came home from work and she and my niece decided that I needed to go to

the hospital. And so I had to go to the hospital. Here we see that this person tends to spend time with family, right? Maybe television is a hobby. What is the person's medical person perception of stroke, maybe drinking coke as a remedy to illness? Is he referring to low blood sugar? We're also looking at the social network, the in-laws, the daughter, the niece. And we also see the importance of family in making decisions. Who does he listen to? His daughter. In the next slide, I got up in the morning and I go to the kitchen to make a lunch. I got a loaf of bread and I couldn't untie it. And I, what's wrong with me? What's wrong? And a few minutes, I was, something's wrong with me.

So I came to the room with my wife and something's wrong with me. I can't. I can't take that bread out. She panicked. They called my pastor, said, "He had a stroke." So call an ambulance and they bring me here. So here we see that the importance of family. He was relatively independent, made his own lunch. There was vulnerability, but also you see the support system, reliance on the pastor to help identify the stroke. And here in this third example, I was at home. I felt light headed after 15 minutes, my aunt from Canada called back and said that I should be brought to the hospital right away. That I had a stroke. So when I arrived at the hospital, I had difficulties explaining. They asked me one plus one, I couldn't answer.

They admitted me, they did an MRI, they saw that I did have something on my left. There was a small clot. That's it. So here we see a cultural component. Wherein a nurse based in Canada, the patient made a long distance call to Canada because the nurse aunt was their support system whom they could consult with. So shifting gears to procedural discourse. And in this model of that would be, again working on the identity, focusing on one's identity. Procedures. These are description of steps to perform an activity in a specific order. It is goal oriented, highly structured and concrete. There is a chronological temporal structure involved and it's based on script knowledge of learned routine. So for example, these are typical routines involved in an activity such as going to the doctor, right? Checking in with a nurse, seeing the nurse

and then seeing the patient and then paying. And the primary purpose is to inform or instruct. Now why do we need to study procedural discourse? Well, there's a supportive context. There's a common contact information for both the listener and the speaker. It can serve as a diagnostic tool, right? How patients with the facial structure information. Verbal rehearsal can be used as a strategy to complete essential activities of daily living. And it can also foster patient identity. So a common way can be or you can use your own procedure, but one way that we've used in research is how do you make a ham sandwich? Give the steps as though explaining it to someone who's never done it before. And then we look at different aspects of procedural discourse. You will have essential steps and a target step or the final step. And then this will also be with sub-steps if they want to include some steps.

So say for example, in the next slide, what are the steps needed when going on a vacation? We can choose a destination, pack the equipment, the person might add several sub-steps, travel and then arrive in the hotel or destination. Or in the next slide, what are the steps in going to the market? We can make a list, get to the market, choose the items needed and the person can provide more elaborate sub-steps and then paying. So what are we looking for when we have our patients produce procedural discourse? We're looking at coherence. Does it make sense? Is there a temporal structural causal relationship and are they using simple or complex sentence structures? Do they have referential errors? Like are they using it, he or she to refer to too many objects and it's hard for us to follow? How is their information structure? Do they mention all these central steps or sub-steps? How many of these were mentioned? And usually it's best to assign these eight priorities.

So the essential steps, these are necessary to complete the procedure. Sub-steps may be additional steps, can support the essential steps. And we also wanna look at whether or not there are non-related steps as in the case of right hemisphere. What has been done in the past on procedural discourse in Aphasia, we're seeing that they have

preserved script knowledge. Those with mild to moderate Aphasia levels tend to structure their procedures well. They use simple language and sometimes have errors at this intentional level. If they are more familiar with the topics, they provide greater number of sub-steps and they tend to have referenced difficulties when it's more complicated, social procedures involved. So in our study that we did when they were talking about going to the doctor's office, there was a nurse involved, the receptionist, there're just too many people that they were having difficulties with reference. So in the next couple of slides, I will be giving some examples on procedural discourse. So this is making an omelet.

So let's take a minute to read through it. So here we see that coherence is somewhat decreased but there is a temporal causal structure or script involved. So they cook the omelet prior to eating it. Looking at the language, it's very simple. There're some reference errors like pour into pan or pour onto plate. As for the information structures, the ones indicated in red are the essential steps like pour the ingredients, cook, put on the plate, ready to eat. But it is missing gathering all the ingredients together and the items that are highlighted in blue are the sub-steps. And this person did not produce any non-related steps. Here's another example, I'm gonna give you a minute to look through it. So here we see that this response is very coherent. There's good temporal causal structure following the restaurant script. When they ask for the menu, they order, they eat, they paid.

There're no reference errors, information structure's very well done. There're essential steps. There're lots of sub-steps. It's very elaborate such as looking at the calories, thanking them for the food, calculating the tip and there're no missing essential or unrelated steps. So how does this relate to identity? It's very important for us to try to incorporate meaningful activities in therapy. So I have several anecdotes of patients that I've worked with. One was a woman who loves to cook and bake. She always gets very animated when talking about steps to cook her favorite dish. And during this time,

she also spoke about her grandmother who taught her how to cook. So I got a twofer. I got a procedure and a narrative discourse as well. Or another example of a gentleman, who used to be in a funeral business for 30 years. He was extremely proud about how he started his business and even gave a procedure on how he would embalm the bodies. Or another patient that I worked with. She was a woman who loved going to the casino. She provided a very elaborate procedural discourse on how she could determine which slot machine would make her win. So in addition to this, I also got a narrative on the day that she hit the Jackpot.

So we can use, definitely use procedural discourse to tap their identity. Shifting gears, we're moving onto conversational discourse and identity. So here we're looking at social network as well as co-constructing competence. So conversational discourse is very important. It is the heart of human communication. It is the root of relationships because we have frequent interactions with others such as family, friends, neighbors, healthcare workers or caregivers. In the context of Aphasia, our goals for communication are information exchange and a social interaction as well. We're trying to look at context which are natural, authentic, relevant to the person versus looking at discrete elements of language. And the idea is that communication is flexible and it's multi-dimensional and, therefore, we're trying to study the collaboration between the person with Aphasia and their partner versus just focusing on the person with Aphasia.

And we're also looking at adaptations to impairment as well. Conversation is very fundamental to self identity. Through conversation, a person develops and maintains a notion of self, they try to meet emotional needs and we also build social relationships. So one recognizes and affirms their current identity as a person with Aphasia. They address the social and personal consequences of Aphasia by conversation and it becomes central to life participation. Now this next slide, I'd like us to think about it. Step back and just think about these statements. Improvement in language does not necessarily translate to improved quality of life. Decreased quality of life results from a

loss of identity. So say for example, we have a person with Aphasia, he used to be nonverbal, now discharged because he can point to objects in this room. This does not necessarily translate to being able to communicate in personally meaningful contexts and can still result in social isolation and depression as well, which is the reason for the next slide. It's very important for us to begin with the end in mind, which is having the ultimate goal of social integration in a supportive environment. Now the way I like to think about is it's like a physical therapy analogy. When a physical therapist does the assessment and sees that the patient needs a walker, before discharging this person with a walker, he wants to utilize sessions with the Walker in various functional contexts and then discharges the patient.

And when the patient is discharged, he needs to make sure that the person has a walker with him. And like manner SLPS, we are trying to move the patient with Aphasia from individualized sessions and then moving them out, right? So it's important for us to definitely identify these key persons. Once we've identified them, we teach them the strategies, try to emphasize the values and hopefully this will transition them into a more supportive communicative context upon discharge. So partners definitely matter. Persons with Aphasia who are surrounded by willing and supportive communication partners are more likely to engage in social activities post-stroke. So what are some things that we need to do? We can't identify the social support system.

Who are these key individuals who can support the person that Aphasia and improve their communication? We have to recognize the essential role of the family. As Hinckley mentioned, stroke is a family illness. There is medical care, practical help facilitating the role change, trying to encourage the patients and provide independence. Once we've identified the support system, it's important for us to try to observe and interview who are these significant others, doing a social network analysis? Where do they interact the most before they had the stroke? What would they like to maintain? Then we assess, looking at how do they collaborate and then what are important relevant

contexts for the person with Aphasia? And then we train the individual and their partner. So conversational discourse is a strength-based approach. We look at natural interactions between the person with Aphasia and their partners. Essential features we're looking at are turn-taking, repairing communicative breakdowns, trying to manage as well as maintain topics. Now in my first lecture I did cover a couple of these and for today I wanted to share some sample strategies. So for the person with Aphasia, we try to encourage them to use different modalities, right?

And then we try to encourage them to also request for help or request more time. For the communication partner, we're also looking at, are they able to decrease their interruptions? Can they facilitate comprehension via yes, no questions or providing choice responses, can they encourage the use of various modalities and are they able to rephrase the utterance whenever there is a breakdown in communication? In my last lecture, I mentioned on how conversational discourse is often measured via rating scales. And I wanted to focus on these two rating scales, namely the measure of skill and supported conversation, which rates the conversation partner and the measure of participation in conversation, which rates the level of participation of the person with Aphasia.

So as I mentioned previously, these scales are designed to evaluate any conversation between the person with Aphasia, their conversation partner in any context and it captures both the interaction and transaction. And these are similar principles that are used in supported conversation for adults with Aphasia approach. So when we're trying to rate the conversation partner, the theme here is acknowledging competence, whether it's explicitly or implicitly. So for explicit acknowledgement, we can say, I know that you know, at appropriate times, right? Or we can acknowledge frustration when despite their efforts, the communication still breaks down. Implicitly acknowledging competence can be via using a natural tone of voice and not talking as if they can't hear or recognizing the person with Aphasia is an intelligent adult who is capable of

talking about topics that matter to him. For the level of participation, we have getting the message in, getting the message out and verifying. So for getting the message in, we need to make sure that the persons with Aphasia try to understand what is being communicated. So we can use various modalities, gestures, writing pictures, using simple sentences. We try to observe their facial expressions or their body language and try to see whether or not they're still understanding what's going on in the conversation. And we try to eliminate distraction as well. For getting the message out, we are helping our persons with Aphasia express their thoughts.

So do they need yes, no questions? Like are you fond of animals? Do they need fixed choices? Like do you want coffee or water? Is it important to, It's important to possibly use various modalities to help express themselves. And we can ask one question at a time and provide sufficient time to respond and another step is verifying. Sometimes it's helpful to write down key words. It's because we want to make sure that we understand what exactly the person who the Aphasia has told us to ensure that we are both on the same page. Summarizing what you believe that person expressed via recapping or repeating the message so we can say, so let me make sure I understood what you just told me. And another one is expanding on what the person might be trying to say.

And when we employ these strategies, this helps the person feel a bit more valued in the conversational context. This next slide is something that I wanted to take more time on. The concept of saving face. Now according to Simmons Mackey, the concept of saving face is not often discussed in Aphasia rehabilitation. So the loss of face happens when the person with Aphasia often feels that others perceive them as stupid because of the reactions of their listeners when they demonstrate communication difficulties. Hence, it's very important for us to train the communication partners to alleviate this loss of face. Because saving face, the perception of others is highly critical to the communicative success and participation of those with Aphasia. So how



do we go about this? Accepting and accommodating to the communicative style of the person with Aphasia via all modalities. So partners may initially be reluctant to adapt communication behaviors. What they're finding is that good communication partners try to remove the stigma associated with the augmentative communication style and they try to support inclusion. So for example, a person with Aphasia starts writing words, maybe the partner might also adopt written supports. And then another, in doing so, we reveal their underlying competence, which reflects their social identity. Humor is another way through which we might be able to remove ourselves from being the expert in order to provide a framework for equal access to communication.

So for example, we can say, I'm not so good at explaining these things clearly. Let me do that again. We can also identify trouble spots. So this means not talking for the patient and using the patient's words. So when we need to try to do that, instead of talking for them and not using their words, we can avoid face threatening behaviors such as openly correcting, carrying on extended repair, lacking interest or attention, using overly complex language or failing to demonstrate understanding. What they're finding is that when partners are more aware of the concept of saving face, they become more careful to minimizing breakdowns in conversation.

And when there's a breakdown, when repair starts to become face threatening, their partners might pretend to understand the person and orient away from the misunderstanding and utterance to preserve competent social identity. With that being said, conversation and saving face versus making meaning. This is all an interactive tightrope, right? Because you're trying to balance between negotiating, making meaning or listening to our clients and making sure that they have an opportunity to contribute to conversation versus saving face or avoiding embarrassment or stigma which is associated and which may threaten their social inclusion. So in the next couple of slides, we will be looking at examples of conversational discourse and we will take a minute to read through this and then we can look at how this speaks to the

person's identity and what areas we can modify to possibly save face. So I'm gonna give you a minute to look at this. So here we see trouble spots, right? They're talking for the person with Aphasia. When the caregiver says, he usually has chocolate ice cream. So how might we modify this interaction? Perhaps we can use choice cues by saying, you usually have chocolate and strawberry ice cream, which one of these two do you like more? Or we can utilize pictures with various ice cream flavors and say, can you show me which of these flavors you prefer?

So again, saving face helps her reflect positive social identity. I'm going to give you another minute to read through the second example. So here the care giver is asking too many questions at once. Do you have pets? Do you have dogs or cats? Do you have one or several? Here are some ways of modifying this. Maybe we can ask, give the person with Aphasia sufficient time to respond. Asking questions one at a time or asking yes, no questions. Do you have dogs? Wait for the patient to respond. Do you have cats? And then wait or we can utilize a picture. Can you show me what types of pets you have at home? Or we can utilize a number of board. Can you show me how many dogs you have? And in this third example, I'm gonna give you another minute to look at it. So here we see some face threatening acts, right?

Skipping over the person with Aphasia's response when he says plants. This might imply that your, or communicate to the person with Aphasia that we are failing to demonstrate interest or attention. A trouble spot might be not using the person's words if he used plants. So how can we modify this interaction? Perhaps acknowledge frustration and competence by saying, I know you're trying to tell me one of your favorite flowers. You know what you want to say, except that the words are at the tip of your tongue and you just can't get it out right now. Or we can ask yes, no questions while holding a picture of flowers. Are any of these your favorite flowers? And then, can you show me which of these flowers are your favorites? Or we can use fixed choice responses like do you like orchids or roses? And of course, allowing our patients time

to respond as well. So in this next example, can I give you some time to read through this? So here we noticed that the clinician is asking too many questions at once. Tell me more about this? Where did you go? What did you bet on? The trouble spots are talking for the patient and not using the patient's words when he use the word horse. So how can we modify this interaction? Maybe using short, simple sentences. I learned you enjoy horse track racing, do you go often? Wait for the patient to respond. Where do you go? Wait for the patient to respond. Perhaps writing key words like horse track racing or observing the patient's facial expressions or their body language to determine whether they understand. We can also acknowledge responses.

I know you're trying to tell me about your experiences with horse track racing. You mentioned horse. Which of the horses do you usually bet on? And then pull out some pictures. We can provide choice cues such as which horse do you prefer? The black horse or the brown horse? We can also ask yes, no questions. Do you often go to the track? And of course, allowing our patients with Aphasia the time to respond. And in this last example, I'm gonna give you some time to read it. So here we notice that the clinician is asking too many questions at once. Tell me more about this? Where do you go? Sorry. Sorry, let me, okay. So here there're several trouble spots. So the caregiver is openly correcting and carrying on extended they appear like, no daddy, it's I had a stroke, not I stroke. So how do we modify this interaction?

We can verify the response using the person's own words by saying, let me make sure I understand, you had a stroke, you had a headache and then you slept. Is that correct? And when you woke up, you couldn't walk. Is that correct? So giving the person with Aphasia time to respond, we can also say, okay, what else do you remember about that day? Now the most important thing to remember about conversational discourse is that conversation is dynamic. There's no exact formula to teach persons what exactly to do to facilitate conversation with a patients in every situation. So, therefore, we provide them with a range of options for improving access.

Hopefully with time, this interaction between the caregiver and the patient becomes more smooth and they become more aware and more familiar with their adapted personal speaking styles. And so I wanted to shift to co-constructing competence and the empowered identity. So one interesting concept is that one self assessment of as unacceptable as a communicator, can generalize to a self assessment as an unacceptable person and lead to social marginalization. So a disabled identity can marginalize the patients and limit social access because they perceive themselves as outsiders. And so what are we are trying to do is to achieve an empowered identity. So we're trying to promote a positive Aphasia identity. So this consists in developing resilience or the ability to bounce back from Aphasia.

We can get resilience via humor, flexibility, recognizing their intellectual competence, their self-reliance, their persistence to work on a certain task and then we also get optimism and positive effect by encouraging them to find something positive from each session. And hopefully, these strengthen their sense of self post-stroke and these change over time using various activities as well as opportunities. So we're not only providing the modalities, but we're also trying to provide the attitudes as well. Communication partners must not only have the communication tools, but also develop the values and the beliefs that support communication access. So it's very important to look at these values which are recognizing that the person with Aphasia is a competent person.

And given the appropriate support, can be a competent communicator. We also want them to recognize that the person with Aphasia has something to contribute to the conversation and that all parties within the interaction bear the responsibility for supporting participation and access. We also want to stress that there are suitable strategies or supports that can be identified through cooperative exploration. Therefore, through therapy and addressing discourse in therapy, the person with Aphasia and the communication partner try to adopt a new framework. There's respect

for the person with Aphasia and even if it is difficult, they realize that the cost of participating in communication is worthwhile. So Aphasia therapy does not only address improving communication per se, but also trying to construct the beliefs and values about communicative competence, the rules of interactions, their rights and autonomy as well as communicative access as well. So in the next couple of slides I wanted to put together some sample cases. So sample case one. This is a female 80-year old who has children and grandchildren. She used to be a teacher. She watches over her grandchildren now.

She enjoys gardening, canning food, sewing clothes, typical home body, she watches home remodeling shows and she enjoys reading books. She's addicted to shopping sales. She goes out once a quarter with a group of friends from her former workplace and it's called hat of the month ladies. So we take a step back. What is her social network? So we have family, right, "hat of the month ladies," maybe the sales clerks because she loves sales, maybe a librarian when she checks out her books. Looking at narrative discourse, perhaps we can tap the stroke story or a frightening experience or a memorable experience with a family or an unforgettable experience at work as a teacher or how the "hat of the month ladies" began. For procedural discourse, we can look at steps in sewing various clothing because she used to love to sew or identifying a good sale.

What does she look at? Or choosing the best restaurants for her peer group or canning vegetables. Now we wanna look also at the future having reviewed these key persons and activities in her life, are there more important social contexts that she would like to be involved with? So, for example, a conversation with family. Is this something that you want to develop? Conversation with her peer group, reading books to her grandchildren while asking simple questions. Could that be an area? Or whenever she checks out books from a library, can you practice a certain script? Or a script for buying something from a store to facilitate participation in life. Now sample case two, is

that of a 55-year old male who is married with children, used to be a truck driver, loves going to the casinos, loves to travel, enjoys going to the movies, follows a football season closely and gets together with buddies during Super Bowl Sunday, owns a train collection, repairs his old car in his garage and has a dog and he used to play guitar in a band. So stepping back again, looking at the social network, we have a family, people at the Casino, maybe the movie house at the airport, Super Bowl friends. So how do we incorporate narrative discourse into this? Stroke story or producing a memorable experience with a family? Or a memorable experience about how he started playing in the band or a memorable vacation.

Maybe we can also have him talk about how he started his train collection. For procedural discourse, we can ask him steps in repairing an old car or steps in changing a tire or a car battery or if he likes the casinos a lot, trying to identify the best slot machine when he goes to the casinos. Or what is his dream vacation and what are the steps that he looks at to make a final decision as to where he wants to go? So again, looking at the future, are there any social contexts he would like to participate in? Which we can practice in therapy? Simple conversation with family, telling his stroke story to his friends. Maybe scripts at the casino when he's interacting with someone or with his Super Bowl friends or purchasing a movie ticket. Maybe that's something that he likes to practice.

And then we have sample case three. A male, seven seven-year old who used to be a former attorney. Likes to play the saxophone, has children, enjoys having a barbecue in his backyard with friends and family, enjoys the museum, the symphony, eats out at restaurants a lot, enjoys hunting and fishing, watching horse track races and betting on horses and knows each horse by name. So stepping back, what is this person's social network? Their family, their peers, perhaps people at the horse races, the museum, the symphony or the restaurant? Now how can we incorporate narrative discourse? We can ask them about their frightening experience or their stroke story or a memorable

experience with a family or when hunting or a story about the most challenging case he worked on as an attorney, how he started horse track racing. For procedural discourse, we can look at how does he grill steak? What are the steps he looks at when betting on a horse? What are the things that he studies before placing his bet? And what are his steps with fishing or hunting? Again, looking at the future social context, he might like to participate in, maybe having him study the menu of his favorite restaurant and practicing how to order or simple dialogues with family and friends or simple conversation at the museum. What are things he likes or did not like? Or scripts such as betting on a horse.

So these sample cases give us somewhat of an idea of how to incorporate discourse while considering the person's identity. And so it's also important to evaluate their process. Evaluating the journey post-stroke. So we're reflecting on their identity after a stroke to help them reshape their new social identity. Some helpful questions you might ask, thinking about this time after your stroke, what do you think has helped or not helped? Or using a metaphor to describe their life before and after the stroke. So maybe it was initially viewed as a stumbling block and now it's a journey or a battle. And noting these changes in the themes when describing their experiences as well. Or another one we could ask them is how do you think your speech's these days? We try to value the person with Aphasia's opinion, their assessment of themselves and their communication skills and we also gain a shared perspective. What is their attitude towards recovery? Do they need counseling?

But we must also note that the needs of persons with Aphasia change and they continually, we need to continually evaluate these changes over time. Try to identify ways to facilitate participation in valued activities. Now the next slide, this is beyond the scope of this course. But I wanted to put it out there that the main challenge for us as clinicians is to go beyond the clinic and to plan communicative interactions, which are designed to ensure successful language use in social interactions. We have

Aphasia groups and they're an ideal forum for renegotiating identity with a person with Aphasia and their significant others. And even Simmons Mackey would stress how important Aphasia groups are and how they must be part of a continuum of care to address reintegration into the community. The good thing about Aphasia group is it's a social space. They can affirm their identity and competence. You select topics or activities that are related to their identity. It provides emotional support. It's a shared social experience of the stroke and they have a commitment to move forward. Another one is mainstreaming into different social environments.

So say for example, we have studies wherein, there's a person with Aphasia who aspired to be a doctor and because of the stroke he can no longer practice. So he ended up volunteering at a hospital as a volunteer or a peer visitor to others who've had a stroke. Or another example cited was a coach. He was a coach of football team of his son. After the stroke, he still became an assistant coach because he wanted to still remain connected to his son. And this sustained his identity as a coach as well as his dealings with his son as well his relationship with his son. Or another example, a person who used to be part of a book club and that is quality of life for them. So maybe transitioning them via a book club with optional worksheets.

So again, this is all beyond the scope of this course, but this definitely is food for thought for us. So in conclusion, it's important for us to begin with the end in mind. We are trying to promote a positive social identity where empowerment is essential to communicative participation. We want to capture the entire spectrum. Individual deficits to life participation. We want to look at their identity, who were they before the stroke? Their perspectives on having a stroke, where do they envision themselves to be in the future? With empowerment, we are trying to have them identify areas of competence, formulate their outcomes and then highlight these competence. It's also important for us to implement activities that transition the patients from a therapy context to a social context and to begin this, it's very important for us to identify the



key persons. Teach them the strategies, impart the values which form and empowering identity that communication is worthwhile. And hopefully this will facilitate social environments that will affirm their identity and their competence. It's also important for us to assist patients with Aphasia as a renegotiate and reevaluate their needs across time. So their change needs change over time. We need to identify these needs and try to find ways to facilitate participation in valued activity. In conclusion, I'd like to conclude with something that Hinckley mentioned in her article on describing identity and stroke. After stroke, you're not the same person as before. The changes may be slight, but they are still changes. It would be wise if everyone, most particularly the patient accepted them, but of course, the patient doesn't want to. He wants his old self back, whatever the defect, he's familiar with it and this can be disconcerting. Reflecting on this, I'm reminded of the importance in helping our patients renegotiate their identity. As Worrall mentions, a person with Aphasia would gladly trade accuracy on a therapy task for an interaction which acknowledges them as an individual and not just a disorder. Therefore, it's essential for us clinicians to not only see the diagnosis but also to recognize a person within, to value their identity and help them to regain a positive sense of self. And so this concludes my talk for today and I'd be happy to answer any questions you might have.

- [Amy] Thank you so much Dr.Santos. I'm taking a look at the quick Q&A box here. I did wanna let our participants know if you do need to leave, you have been here for the full time, so you'll get credit. If you wanna stick around for a couple of Q&A's, please do. We have actually more of a comment here that just says, I have my patients engage in real communicative interactions around my facility with other staff members, with my support such as verbal, visual, written models as needed. I think it really helps promote generalization. Very good. And then someone else is asking here, what about persiveration and short term memory loss for carrying over learning from one session to another, when does the SLP know that the intervention is really working in a time when limited treatments is a limited factor for ongoing therapy?

- [Tricia] That's actually a very good question. And one of the studies done by D'amico and colleagues is facilitating authentic communication wherein he strongly recommends that a person and their partner be recorded for an amount of time and then trying identify behaviors which are consistent and which may be impairing communicative competence. So in a case study that he presented, he was talking about a gentleman who would try to do word retrieval and the word retrieval came on, it really became extended to the point that he couldn't really communicate his thoughts. He was getting more frustrated. And so when they videotaped this whole thing and made the patients watch it and the caregiver, he could see that yes, this behavior is definitely not helping in a conversation. And so they were trying to address, trying to limit word retrieval deficits and when he would easily identify that, oh, I'm getting stuck in the loop of trying to retrieve words, then maybe I should use gestures or written language. And with time he was able to become, having heightened awareness of when he was getting stuck in the conversation and when to move on. And similar with, they were also educating the caregiver as well that when these behaviors were coming up, then maybe the caregiver can transition. So to answer the thing on short term memory, perhaps having written cues, right, writing down on a sheet of paper of what the topic is about so that you can maintain and manage the topic. That might be an area that you may explore.

- [Amy] Great, thank you. And I think we're just gonna try to cover one more question here from Sylvia. what strategies do you find helpful with caregiver family training in a small group or how do you usually do it? She says that a lot of the families she works with are very large. They have limited times. They can meet with the therapist,

- [Tricia] Right. And that is a problem. However, I do try to emphasize the importance of saving face. When I put that in the forefront, that it's important to try to save face, then they are more on board. And I tried to explain how a lot of persons with Aphasia tend

to say that they think that I am not intelligent, but Aphasia is not a problem with intelligence. And when I educate them on that and the importance of saving face, then they're more likely to say, okay, what are some strategies? And of course, providing them with a handout on some basic things that they can use. And then when the caregiver's there, then I immediately shifted to the caregiver trying to demonstrate the behavior and then shifting to the caregiver and allotting some time of the therapy wherein the person with Aphasia and their partner will be able to communicate.

- [Amy] Right. And that seems like a comment that most people are gonna be able to understand. We all wanna be seen as competent, smart people and not be treated otherwise. And so I think framing it in that the saving face term probably makes it easier for caregivers or friends or whoever else to get behind it to sympathize and understand.

- [Tricia] Oh yeah, I get that.

- [Amy] All right, well I think it's five after. Thank you so much to our audience for some interesting questions. If anybody has other questions, I note that Dr.Santos's email address's on the slides. Tricia, thank you so much for being here with us today. It was a really interesting topic and I enjoyed hearing a little more in depth about narrative intervention. So thank you so much for your time.

- [Tricia] It's my pleasure, Amy. Thank you so much.

- [Amy] All right everybody. I'm gonna close up the meeting here. I hope everybody has a great afternoon and that we see you at another event before too long. Bye, bye.