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Ethical and Legal Issues in
Dysphagia Management, Part 1
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- [Amy] All right, well hello and welcome to our webinar with Denise Dougherty this afternoon, she is presenting part one of our Ethical and Legal Issues in Dysphagia Management series. This is part one of a part two series. And Denise Dougherty owns and operates a private practice in Indiana, PA where she conducts therapy with children and adults. She received her bachelors in communication disorders from Marywood University and a master's from St. Louis University. Since 2007 Denise has served on the Expert Work Group of the Physicians Office Quality Measures Project for Quality Insights of Pennsylvania, working on initiating quality measures for CMS to improve effectiveness, efficiency, economy, and quality of services delivered to Medicare beneficiaries, specifically a medication review. She is a past president of the American Academy of Private Practice and Speech Pathology and Audiology, a past member ASHA's Healthcare Economics Committee, and a co-editor of Private Practice Essentials: a Practical Guide for SLPs. Denise works as a forensic speech pathologist and expert witness in litigation involving dysphagia, choking deaths and surgical errors. So welcome Denise, thank you so much for joining us today.

- [Denise] Thank you. So we have a lot of information to cover and I just want to let you know that there may be some information on the slides that we won't spend a lot of time on, but it's there for your review. We want to do some discussion about the topic. So this is part one, eagle, eagle. Ethical and Legal Issues in Dysphasia Management. Financial disclosures, as Amy said I am in private practice and I am receiving an honorarium from SpeechPathology.com for part one and part two. My non-financial disclosures, I do serve on the governing body of the Home Health Agency in my area and also the Quality Insights of Pennsylvania, specifically the medication review. So we know that when we are working with our dysphagia clients, doing the evaluations and therapies we have many challenges that we have to deal with, not only with our clients but families. So specifically we're going to talk about the code of ethics and relating it to dysphagia practice, and we'll spend a lot of time on the evaluation, need for the chart review clinical evaluation and justification of therapy services, and we'll be

touching on competency throughout part one and part two. so our learning outcomes, you should be able to explain the ASHA Code of Ethics and how that relates to dysphagia practice. Describe how to self assess your own competency related to dysphagia assessment and treatment, and then to describe how a complete and thorough assessment properly documents the presence of dysphagia and justifies skilled service. So when we take a look at our clients and our job responsibilities and the code of ethics, patients have great expectations of us. So what they expect is to have a provider that is competent, we should know what we're doing, that is an expectation. They also expect we will treat them with respect, so we need to listen to them and hear them, what we often see is their complaints being dismissed as that it's not important. So we do need to hear from our patients what their concerns are and take that into account when we're working with them, not only in the evaluation but in our therapies.

They expect us not to harm them and to act in their best interest. So we need to look out for them and help them improve their quality of life. When we're looking at health care principles, there are four that we need to keep in mind. The very first one is autonomy, so we need to be able to honor our individual's right to make their own decisions. They may not be decisions that we would like them to make, but it is their choice and it is mandated in the self-determination act. So as a general rule, a person who knowingly and voluntarily engages in a risky activity effectively assumes the risk and waves the liability for any resulting harm. So just as when you get in your car, you have the choice, do you put your seat belt on or do you not? There's risks that go with not using the seatbelt, there's also risks that we see with our patients when they decide they don't want to follow the recommendations and that is their choice. We also need to look at beneficence, and this is seeking good for the individual, and then nonmaleficence, we are not supposed to do harm. The last one is justice, we need to be fair and treat all individuals alike. When we look at malpractice, I need to tell you, patients' families do sue. Many times there will be a lawsuit that claims negligence,

wrongful death, breach of standard practice of care, and lawsuits do take years to settle. It is a very complicated process with medical record reviews, depositions and trials, so it can take sometimes five years before a lawsuit is settled, and the family may not sue immediately. So the only thing you have to go on is your documentation. A dietitian I work with on some cases has told me that she has about 20 lawsuits that cross her desk every month related to a choking death or an aspiration issue. So we do need to recognize this does happen. We have a professional liability, a legal obligation to compensate patients and/or families for injury or suffering that are caused by acts of omission, we didn't do something, or we did something as the professional in charge of their care.

So it's a patient right to make their choices and it's difficult whenever they do that because it can actually impact our productivity. How many times do you have a patient that says I don't want therapy today, I'm not gonna participate at all, I'm not gonna eat or drink that stuff, and it really throws a monkey wrench into the therapy time that we have completed for that individual. We also need to be very careful when we're in a facility and they're expecting us to be 100% productive. There is no way all of your time can be billable in a facility and then it really poses the question, was there something fraudulent that took place to allow you to make 100% productivity.

A lot of individuals end up doing documentation off the clock on their own time and that is not fair to us as the professional, it's part of our job and we should be able to get it done in the work day. But difficult to do in some facilities. So when we take a look at our code of ethics, exactly who does it apply to? Just about everybody actually. It applies to members of ASHA who have their CCCs. It applies to members who don't have their Cs, non-members who do have Cs and applicants. So everybody needs to pay attention to the code of ethics. When we are looking at dysphagia, we recognize it is a high risk specialized area within our scope of practice and many times what ends up happening is people believe that once you have your Cs and your license, you're

competent, and that is certainly not the case. There's a lot of documentation that suggests that just certification and licensure are not enough to ensure your competency. So when we go back and take a look at your dysphagia education, exactly what did you learn? When I went to school in the 70s, we barely had the definition of dysphagia. We knew how to spell it, we knew how to pronounce it, but not much else. So unfortunately back then we learned on the job and we did a lot of reading, we did a lot of continuing education and things have changed, but there's still a wide variation in the type of courses we have in graduate school that touch on the dysphagia component. So competency is a huge deal in our code of ethics. And you'll see multiple times throughout the code of ethics that all services should be provided competently and we should only engage in those aspects of the profession that are within our scope of competence. So how competent are you to provide treatments for many of the disorders that are out there? We need to really take a look at our own skill level.

So when we take a look at the code of ethics, we have principle one, two, three, and four. Principle one really is spending a lot of time talking on delivering services competently, and if you can't then you need to refer, have someone else treat this individual. In principle two it is our job to ensure and maintain competency, and we have certain credit amounts that we need to fulfill for our state requirements for licensure and for ASHA, but it is our job to make sure that we meet that criteria for our continuing education. It's our responsibility to be competent. So again, what have you done in your career to ensure that you're a competent, especially with the dysphasia type of individual. So courses, reading, asking for mentoring if you're not sure about your skills, especially if you're early on in your career. We also should not be guaranteeing that we're going to get this individual back to regular diets and thin liquids, sometimes that's not possible. So as much as we would like to advance the to the highest appropriate diet level or the least restrictive, it doesn't necessarily mean it's going to be regular food and thin liquids, sometimes it's not possible. We also have to

be very careful about patient abandonment, that is a real red flag for malpractice, and what sometimes happens is the patient refuses to follow through with the recommendations, so we automatically discharge them, and that's something we have to be really careful about. That is a huge red flag. Just because they're not following through with what you believe should happen doesn't necessarily mean you can't continue to work with them either on education, teaching them strategies or still having them participate in therapy to make their swallow stronger so it's much more effective so be really careful with that, that's a huge red flag. We also need to look at our documentation, the records that we are putting into this patient's chart. So I suggest that you go back and review some of the previous notes that you've written in the last week or two.

And read it, what did you leave out? Sometimes in our hurry to get that note done and get it out of the building before we make a difference in our productivity we left things out and it's really important that our session note actually reflects what happened in that time with the patient. Does it accurately represent what happened? So what's missing? Usually what I see whenever I do record reviews is the lack of documentation on education of the patient, of the family, of the caregivers, of the staff, that really needs to be in there. We do it a lot and we forget to write about it, so that's really important that we make sure that we're documenting the education that we do on a daily basis.

When we look at principle three, this is looking at how we do business, so marketing and fraudulent claims. And then principle four, how we interact with other professionals, the multidisciplinary team and to increase the quality of care for our patient. So as we go through the code of ethics, I recommend that you go to ASHA's website, and you just review, download, print out the code of ethics so that you can get a better feel for it. I've just taken snippets out here, so again when we're looking at the code of ethics, they are a real stickler for competency. When we are looking at

point H, we need to obtain informed consent, so the patient and the family needs to know what is going to be the nature of the treatment, the possible risks and effects of services, we need to let them know that. What technology or treatment techniques are we going to use, what products are we going to bring into our therapy session or suggest that they purchase for exercise programs? There are possible effects when they don't engage in treatment or they don't follow the clinical recommendations. So we need to make sure we're informing them about the evaluation results, about the need for a therapy, their diets, and their liquids, so how do we educate whenever we're talking to our individuals? So we need to make sure we're looking at handouts or literature that we can leave this individual and their family to review at their own pace. We need to also be careful when we're communicating things to our patients and the families because we go to school for a really really really long time to learn the big words and then we can't use them with anybody because no one knows what we're talking about.

You know, I love the word xerostomia, but can't we just say dry mouth? We need to take it down, sometimes a couple notches before the family and patient actually get what we're trying to communicate to them. When I do my home health patients, whether it's the patient that came in with a Modified Barium Swallow or somebody that we've sent out and they've come back, we also always give them a Modified Barium Swallow handout and on the front we have the anatomical drawings so we can talk about, this is what we look at, these are the structures that are involved in your swallow, this is how they should work, and this is how they work for you. And then on page two we have the identification of the diets, and we're using the IDDSI diets, not the National Dysphagia diet. So what diet level are they on? We're looking at strategies that they need to use, whether it's chin tuck, should they use a straw, no straw, being upright, those types of things, and then the red flags that they need to watch out for so that they can call the office or they can call me and say we have a concern. We need to also understand that our patients and families put their own spin on what they've

heard. That's not what they were told but that's what they took out of this discussion. I can't tell you the number of times I've heard from a family the speech pathologist said the food is going down a hole, can't we just sew that up? Well that's kind of called the airway, and that's not a good thing for us to do. But that's the only way that they can explain it or perhaps that was how it was explained to them. So just a different spin. If our patient is not able to make decisions competently, they lack decision making capacity, we need to figure out who is the person that's going to make the medical decisions. So is it a spouse, a family member, do they have a power of attorney? If you're not sure, you need to check with a social worker, they tend to be pretty on top of who is the power of attorney.

And we also need to make sure that we've looked at the advance directives because the recommendations if we're going down to the level of MPO, it may actually be against their advanced directives and we need to honor those, that is a legal document. When we're looking at prognosis, we can't guarantee that there's gonna be a real positive result, we're gonna certainly try, but they need to make sure that they understand they need to be very into participation. If they are of the mindset I only need to do these exercises when the speech pathologist is here, that is going to limit what we're able to do for this individual.

And we need to look at evidence based practices and use our good clinical judgment, but keep in mind that you over the years have picked up some expertise, and you've seen some techniques work with your individuals. And I would suggest that we keep that in mind, that we do have some experience that we can draw on when we're working with individuals and try different therapy techniques. We also need to make sure that we're accurately billing for services, and this is where we need to look at our documentation because when Medicare or other insurance companies look at it, they're trying to decide is your note documenting skilled services or does it really suggest what you did was unskilled, anybody could do this? So keep that in mind

when you're doing your documentation, we'll talk about that skilled versus unskilled in part two. When we're looking at honoring the responsibility, we need to make sure that we are at our highest level of professional competence and performance, and you hear all the time from ASHA, work at the top if you're licensed, it's our responsibility to make sure we're doing the best job possible for individuals. When we're looking at our clinical fellows, or mentoring them, supervising and teaching to help them improve their skillset, when we're taking a look at our new hires, sometimes they come from a different type of facility, we have a lot of individuals entering the medical speech pathology field that have worked in schools, so it could have been years since they had any type of dysphagia training, or clinical experience with that individual. So we need to make sure that we are doing our jobs as supervisors to make sure that the individuals practicing really know what they're doing. When we look at point D, lifelong learning, dysphagia is one of those areas where things change rapidly in the field, so you always need to be on top of our continuing education.

We need to be really careful if we're in an administrative role or a supervisory role that we're not permitting our professional staff to provide services that they can't do competently. So keep that in mind, they may not be ready to perform the modified or the fees or sometimes even to do an evaluation by themselves because again there has been this gap in their education or their experience level, and we don't want them to work with our patients until they really can do it competently. We have to be careful with fraud, there are a lot of speech pathologists serving prison sentences for fraudulent billing, not specifically in the area of dysphagia, but in the other type of treatments that we might provide for our clients. I've seen people look for codes that have a higher reimbursement level, because the one code that I should be using pays very poorly and we shouldn't be doing that. So with dysphagia we just have a limited number of codes which helps that particular issue. So we need to make sure that we're looking at our financials and not financial statements. We are making sure that we're putting everything into our patient's notes and doing our therapy. We also should not

misrepresent our credentials or our competence, education, and training. So if you haven't had a lot of experience, now is your time to make sure that you at least do the course work to get that under your belt. Okay, so when we take a look at some of the surveys that ASHA has done, one in 2017 found that speech pathologists who were working with adults, 39% of the case load had a dysphagia component in pediatric speech pathologists, they were reporting about 16% of their caseload had dysphagia. And when we look at individuals who are working in the acute care setting, more than 50% of the caseload is dysphagia.

And now we're seeing the dysphagia individual being treated in the school system. So 2018 they found about 14.5% of speech pathologists have a caseload involving dysphagia. So medical speech pathologists have often discussed they don't feel consistently competent about when to provide dysphagia services. And we've talked about there is so much differences in the amount of graduate coursework that you've had, your placement experiences, your ability to do evaluations, so we need to make sure that our competency is as top notch as it can be. What was your clinical experience? A lot of individuals think dysphagia services is really just watching the patient eat and drink or the entire therapy plan. And that really isn't the case, we need to keep in mind therapeutic exercises are a part of what needs to happen with our individuals.

Be really careful about rapid upgrades, whenever we take someone up the food chain we need to keep in mind that that increased texture and thinner liquid consistency requires increased muscle strength to be able to control the bolus, so if you are rapidly upgrading them, they may not be able to handle it, they fatigue quickly, they don't have the muscle strength or the endurance to meet their needs three meals a day for that, so we can see some real problems. What is the impact of dentition on the patient's swallow? So we need to keep that in mind in our evaluation as well. There could be some pressure to efficiently manage our team, so supervisors who really want to

address those inconsistencies in skills and service provision really can't do the job that is required because of pressure from the top down. And if you're in an administrative position, sometimes productivity needs to be maintained and there's less of a concern about the competency level, and that can come back and hurt you later. What they found is, in studies, speech pathologists commonly use swallow techniques that don't even correspond to the patient's symptoms or physiological abnormalities that were seen on the video swallow study.

So we need to keep in mind that the Modified or the FEES is not just to document aspiration or penetration, it's to tell us what's working and what is not working so we can focus our efforts on the exercises and therapy techniques that will make a difference with this individual. Our outcomes and reimbursements are tied together more than ever before, so we want to make the best use of our time and improve our patients' quality of life and their skills. So for a lot of those reasons, they've come up with what is called a Dysphagia Competency Verification Tool and there are skills listed in six different areas, and this goes back to principle one 1-A where we're providing services competently.

And we know that certification and licensure is just not enough. So when we look at this tool, how do we use it? Well if you're a relatively new hire or a clinical fellow you can use this tool and our supervisors can use this tool to make sure that these individuals have the knowledge and skills to provide the dysphagia services safely. And if you're the experienced individual, we can use this to track your skills and you may want to use that information when you're going for the certification and the swallowing and swallowing disorders. When we're looking at the Dysphagia Competency Verification Tool, these are the different areas that you can be assessed. So we have the assessment and treatment, we have the Video Fluoroscopy Study, we have the FEES. High-Resolution Manometry is a relatively new field, there are some facilities around the country that are using this, so you may do a modified and it could look pretty

decent, but when you do manometry, there was a probe in the pharyngeal area that is checking the pressure and we might find that even though the Modified looked okay, it's a pressure issue. So it helps us with our therapy program, so that is going to require a lot of equipment and training. So are you competent in that type of evaluation? We also are looking at continued competency review and advanced competencies. When you go to ASHA, their website, you can see the different type of knowledge and skills needed to provide the Modified Barium Swallow and the FEES, and there's also a link where you can check out these specific endoscopy requirements per state. So if you're not sure you can access that information.

There is a new concern and this is, if you've been following things on ASHA's website or in the blogs, with the patient-driven payment model, we're seeing and hearing that some speech pathologists have already been terminated because of this new payment system coming into play or their contracts have been changed. When I was early on in my career, we went from a 40 hour work week to hey, we'll call you when we need you. Or we got a phone call in the morning saying based on your caseload you need to be out of the building at 12 because we can't justify your presence at 12:30. So it changes everything. So we're still supposed to provide the same level of care that's justified under the payment system we are currently using.

And the reimbursement remains unchanged when we go to the patient driven model compared to the previous payment system. Some facilities have actually changed their treatment times to 15 minute sessions and I'm not sure what you can actually get done in 15 minutes. Tim Nanof is part of the ASHA healthcare economics team and he's the director of healthcare and education policy, so he works very closely with CMS and watches the policies. And he has come out in some of the publications from ASHA and said this treatment approach is unethical, it violates the clinical judgment of the therapist, it cannot meet the individual needs to the patient, and it breaches the Fair Labor Standards Act. So rehab agencies and SNFs can't break the law. So that's going

to be an interesting process as we change into that model. When we're looking at the evaluation, we need to start with a chart review and completing that evaluation. Our report is a reflection not only on us personally, as the person who did it, but our employer. So important that we make sure that is a very thorough report. This report has to stand when there is a lawsuit and people go to court. So if you are sued and had to testify, is this report going to help you out or are you missing a lot of information that you wish you had written down? So make sure that when you're looking at your report you're documenting areas of need, you're connecting your recommendations and evaluation to other things that we found in the medical history, it's been professionally written and we're using our terminology. Some things that can trip us up is we have documentation that's very generic, it doesn't really sound patient specific and it's contradictory.

We may say that the pharyngeal phase was normal, but we justify therapy by saying we're going to work on the pharyngeal phase. So it can't be both, which one is it? So take a look at what you're saying? How can we know where we're going if we don't know where we've been? So we need to make sure we're really going back to look at those medical records. Why was the patient referred to you to begin with? So was there a particular diagnosis that triggered the referrals, did someone observe something that was a red flag? Were they treated for dysphasia before they were admitted to your facility?

All that information is important in the medical records and the conditions. I see all the time in reading medical records and depositions, sometimes it looks like the speech pathologist wasn't aware of specific patient diagnoses that were important, such as Parkinson's or dementia. So you need to make sure that you know what disorders, disease processes are relevant to your patient and the swallow that you're currently seeing. We need to make sure that we are doing all of our documentation. We need to look at admittance reports and discharge reports so we can get the information that

makes our evaluation complete. That accurate history is the foundation for our patient care, so we can't plan our treatment without it. We need to make sure that we understand the importance of looking at medications, very important that we look at that. What we know is our patients see a lot of doctors and each one of them are going to prescribe medications and sometimes they're not aware of what else the patient is taking. We see this a lot without patients in patients who are being seen by home health. We are just relying on the patient to tell us the truth. We need to make sure we understand about drug drug interactions. We have a lot of patients on multiple medications that cause lethargy, decreased level of alertness, we need to be aware of that. Medications that cause swelling of the lips and the tongue and the throat. So when you're working with your individuals and they say you know my tongue feels really large, that could be a medication side effect that's really important. We need to look at food drug interactions, what food should they avoid? Grapefruit and grapefruit juice, green leafy vegetables, important that our patients know that. There is a download I wanted to give you the information for.

This is a real easy booklet for our patients to read and it's talking about avoiding food/drug interactions. So I'd recommend that you take a look at that. There are a lot of individuals especially with neurodegenerative disease processes that are using food to treat their disorder. They are using food to slow down the progression or provide them with more vitamins and minerals, and that is called Nutraceuticals. Patients who have neurodegenerative diseases might be using foods that are high in antioxidants because oxidative stress in the brain has been linked to developing those particular disease processes. Are they using natural methods to deal with constipation? Are they doing high fiber foods instead of the laxatives? Are they drinking coffee to stimulate the bowels? And Gummy Bears, they have sugar alcohol, and that is called a polyol and that is classified as a functional fiber, so some doctors in my area are suggesting that you have some gummies to help you along. We need to look at drug herb interactions because many of the herbs just by themselves create oral lesions, so that's before we

even put it in with our traditional prescription meds. So I would recommend that you take a look at some websites. The ones I like are [medscape.com](https://www.medscape.com) or [drugs.com](https://www.drugs.com). [Medscape.com](https://www.medscape.com) and [drugs.com](https://www.drugs.com). Both of those website have drug interaction checkers so you can put in all of your patient's medications and it will spit out a list of oh my gosh, these meds taken together really increase the lethargy component, so I'd suggest you take a quick look at that. So that chart review needs to be very thorough, we shouldn't take shortcuts. And unfortunately when we're new in the field it's gonna take a little bit longer to go through this process, but it is beneficial, you need to know this information. So what is their medical diagnoses, comorbidities? We need to know how those progress and impact each phase of swallow.

We need to know the impact of medications so we can write something such as patient is on X number of medications including PRN and that places them at risk for side effects. It helps us determine what questions to ask our individual when we do the face to face evaluation or ask the family. And it helps us determine what referrals we might need to make. It helps determine what instrumental assessments we might need to recommend for this individual. Patients aren't always accurate in providing information. They can either be a poor historian or they just don't want to tell you on purpose. There was a study that found patients' perceptions of their dysphasia was only accurate in 48% of the patients, and they looked at I believe about 3,000 individuals for that study. So we need to recognize that knowing what happens in that disorder, we know what we should be seeing with this individual as they go through the progression of that disease process. So you can take a look at the speech language pathology medical review guidelines, and it outlines what you should be able to do or should do in our non-instrumental evaluation. And I would recommend that we take a look at using a dysphasia evaluation that might be out on the market, there's a number of them out there. The benefit to using a published dysphagia assessment is we have a test, we have a form, we have criteria that comes up with the score. So we can score how they manage saliva, how they manage their food and liquids. We can score their

muscle movements. Some assessments actually allow you to rate the severity of dysphagia based on the score and the risk of aspiration. So again we're balancing off criteria, it's not, oh I think so. We've got a score, we've got a criteria that we can pull this information from. And you might need two assessments. One for the individual who can follow directions and one for the individual who can't. We need to look at real world feeding ability, because some of these assessments, you're just doing a sip, a bite, or a trial, so you're not going to see fatigue that can actually kick in when they're in the dining room.

So the results may actually be just a little bit misleading. But keep that in mind, it gives you a basis to start with and then you need to move on. The Patient's Self Determination Act of 1990 indicates that patients may consent to or refuse intervention, it is their right to determine what they want to do and what they don't want to do, and we need to respect that even if we think it's an unwise or an unsafe choice. But here's the kicker, they need to know what the consequences might be if they choose to opt out of the recommendations. They need to be making an educated informed decision, so they need information from us, the professional so that they can weight the benefits and the burdens, that's really important. You can't make an informed decision without the information. Many times they decline our thickened liquids and we label them as noncompliant. If you have educated them and they've made an informed educated decision, they can't be noncompliant, they made their decision and we need to respect that.

So be very careful about labeling someone noncompliant when they were able to chose what they wanted to do or not to do. Colodny found in the study of 190 nursing home residents, 40% we deemed noncompliant with the recommendations. So it puts us in an interesting spot. They can choose to do what we're saying or they can refuse to do that completely, and again we need to recognize that decision. Many of our patients give us a hard time in therapy because they don't understand the reason why

they have to do this stupid exercise because nobody has ever told them the benefit of the exercise, what this is going to do for your swallow to make it safer. Now there is shared decision making and we need to involve the patient, sometimes the family when we are coming up with interventions and outcomes, we know that eating is a very big part of quality of life and diet modifications may not be seen very positively by individuals. We have culture, we have social values, we have many different value systems and beliefs that can make or break that recommendation. There could be ethical considerations when we restrict their decision making power for food preferences. And then if we think that their food preferences may be harmful, what does that do to their shared decision making?

So this needs to be a very positive discussion and people need to know. We need to understand the food culture so that we can make the recommendations within the structure of the diets that our patients really want. Sometimes a modified diet from a male's perspective is seen as weakness and they won't eat that in front of their friends because it means that I'm not the macho guy. So there's a lot of tension between safety, quality of life, patient choices in what we need to do as far as rehab. There is a three step algorithm, quality patient/family education and then repeat education so we can continue to talk about the importance of follow-through with our recommendations.

And then we have a team meeting to critically evaluate the risks. When you hear bad news, you stop listening. And you never hear the rest of their explanation, so when you go into work with them tomorrow, they're looking at you like oh my gosh, I didn't know I aspirated because they didn't hear it the first time. So we need to do that repeat education. Everybody is throwing information at this individual and the family and they can only absorb so much. So the more we can give them something in writing that they can review it at their own leisure, it can make a difference for that diagnosis and recommendation to sink in. We need to make sure that we are doing good education,

we have written materials that we can work through with our individual. Instrumental assessments give us a lot of information in addition to the bedside, especially when we're looking at the pharyngeal and esophageal phase and if you can, do an esophageal scan and a Modified. Many disease processes plus aging attack the esophagus and sometime it happens very early on with Parkinson's, even before the diagnosis has been made, there's already changes in the esophagus and its function. So we need to keep that in mind. We also need to make sure that when we're doing the instrumental assessment we are looking at real world feeding ability and the type of foods that our patient will consume.

And if they're eating an ethnic diet, they may have to bring that. I went to Hawaii with my daughter and son in law over the summer and breakfast at McDonald's is scrambled eggs, rice, and Spam. So rice is a huge component of a lot of individuals diets, we need to look at that. It's not often what we would normally consume, we need to keep that in mind. That Modified, that FEES needs to be customized for what is important to learn about that patient. Now the standard practice of care states that if a pharyngeal dysphagia is expected or the patient is at risk for pharyngeal dysphagia, an instrumental assessment must be done.

But there are doors you can walk out of. Number one, the patient is unable to participate, and I would put in that little qualifier at this time. So document, you recognize the standard practice of care indicates you should get an instrumental assessment, but the patient is unable to participate at this time or cooperate, maybe they're too lethargic, they're too combative, things may change down the road, but right now it's not a good idea to send them out. We're not going to learn anything. Or what often happens, those test results won't change how you clinically manage the patient, they've already told you, I am not going to follow those recommendations, I am not going to modify my diet, I am not drinking thickened, liquids, I'm gonna do my thing. So it's a moot point, they've already told you, I'm not gonna do anything you tell

me to do. So we have that door to walk out of, I can't force someone to do a modified against their wishes, they've already said no, so again document, recognize, that is the standard practice of care but patient is refusing stating they will not follow the recommendations including diet modification and strategies, study was not completed. If you don't write that, or discuss why you couldn't get a Modified, if something happens, that's gonna come back on you and they're going to look like you never considered that as a possibility. So document, you know what the standard practice of care is, and the reasons why you could not do that. All right, and we're looking at our education, we know that patients who are in-patients are compliant, and I really don't like that word. But once they're discharged to home, they do their own thing, we know that happens.

You can only control what happens when you were in that therapy session with them in home health or outpatient. They might be motivated to, in a sense, follow the recommendations when they're in the facility because they know if they don't any risk could delay the discharge and they just want to get the heck out of dodge, go home and do their own thing. Also in our facilities, there is limited opportunities for them to get away with something. Now they can still be very clever and share food in the dining room or somebody sneaks something in or a kind visitor had no idea they couldn't have a drink and things happen.

So they can be very clever. But once they leave the facility, nobody is there being the dysphagia police, and it's also very difficult to educate the families because often their work schedule doesn't allow them to come in when they are on the job. So we might actually have to do some sort of meeting time that everybody can agree on or at least a phone conference or a phone conversation so we can share the information. We can't rely on the patient to communicate things because sometimes their communication problems get in the way or there's conflict between family and caregivers and we could have an uncertain prognosis, so all of that can impact how the information is shared or

how people take that information. We always need to look at the benefits and the burdens, the benefits and the harms, especially when we're exercising choice of food preferences. When a patient goes from inpatient settings to another situation, yeah they may be able to refuse the recommendations wherever they have relocated, but they all need to understand there could be health consequences, so this is where we as the professional need to educate. These are the possible consequences of things that could happen including death if you choose not to follow the recommendations or you choose to opt out.

So many times the families hear what they want or they have a misperception. They forget that they're supposed to thicken the soup or the broth and things happen. So when we're looking at shared decision making, we need to make sure that we have adequate communication. We're looking outside the box at alternatives and compromises that may help. We need to empower the patients so that their voices can be heard especially when they choose to opt out of recommendations, and we need to keep our own values and belief systems out of it rather than try to influence them with what our feelings are.

So you can take a look at a lot of these points as we go through, but a benefit of the patient is the whole reason why we're doing an intervention, it can't be for the comfort of the caregiver, and sometimes that includes the staff. I have seen a lot of individuals coerced into signing a waiver and we're gonna talk about that in part two, you don't have somebody sign a waiver because you don't want to do your job and thicken liquids. So we need to make sure that we're following through. We may have to have a lot of meetings, because they can't take in everything at one time, so what are the facts I need to be concerned about when we're making these decisions? And once we come up with a compromise, we have to have clear communication about what that outcome is going to be. We need to make sure that we're looking at risk versus safety, again our patients are free to make a choice even if we feel it is a risky one, and there's

really no black and white sometimes, there's so many shades of gray. And you might have two individuals that are very very similar and have different recommendations for each one of them based on their circumstances and their value and belief system. We need to make sure that we're not labeling somebody as non-compliant when they have opted out and they have done an informed educated decision, but you need to make sure that you have very clear documentation in your records that we've had these discussions, and unfortunately when we're looking at those dropdown boxes on a lot of our electronic records, there's not a lot of room to get into a big discussion, so you might have to do a hand written note and scan that into the medical records.

So again, a lot of information just to clarify that they have the right to make their choices. If they're competent we honor their choices, if they're not competent, then we need to go to a guardian who is going to make those decisions for them. These are everything that our patients need to be able to do, have the ability to do when they make a decision, so looking at competency again, we have to watch that again we're not influencing them with our tone of words, our body language, and we're pushing our value and belief system on them, so can we compromise and find a solution that works for everybody. Maybe if we don't want our food choices, we can find something that's less risky than perhaps what they want.

But recognize that they need to be able to make a choice. All right, we need to make sure that they understand there is a potential for aspiration pneumonia, there is a potential for under hydration, if we do put them on thickened liquids, people stop drinking so many times our physicians actually put the patient back on thin liquids because they're shutting down and they feel that giving them what they want is a better option. So you take a look at the ASHA practice portal, this tells you what third parties should be able to see clearly in your documentation. So again, what is your plan going forward, are you going to be able to alter it based on your patient's response to what happened in your therapy session or are we going to continue with

the same plan based on the response? We need to work out what our patients need, create a proposed treatment plan, and this should be a joint effort between us and the patient and gain their permission to carry out the intervention, so the informed consent. I wanted to list the common ethics problems, so you can take a look at that, but again, make sure that you understand in your documentation if you did not write it, you did not do it. And that comes back to haunt a lot of individuals, so I would recommend that you take a look at the common documentation errors, go back and review some of your notes and see are any of these popping out at you when you review? And then come up with a way that you can improve your documentation, maybe put together a checklist. I need to make sure that I include all of this in my note because we're so pressed for time to get it done. So what we're going to do is open it for questions. Remember part two next time we're going to be looking at waivers and ways we can try to make that shared decision making work for our patients. Okay, so we will open it up for questions if anyone has one.

- [Amy] Yes, we will give it just a few moments to see if there are any questions that anyone has. In the mean time, I did have just one thought that maybe you'd like to share how you handle situations. A patient or family does ask you for your advice and may ask you so what do you think I should do, or what would you do if it was your family member? How do you address those types of questions?

- [Denise] You know, my quality of life may not be acceptable to them, and their quality of life may not be acceptable to me, so I think what we need to do is kind of pull ourselves out of pushing them to make a decision. Heaven forbid I would say oh let's do the PEG tube and things go badly and then they say I wouldn't have done it because you said, and look what happened. So I prefer to lay everything out, this is what we saw in the evaluation, there was a concern, this is what we found in instrumental assessment that was a kind of concern. For those reasons, this is a recommendation for the safest diet and liquid consistency. These are the strategies

that we believe will keep you safe and be very careful about chin tuck, because if you haven't tested chin tuck you don't know if it works, it can actually cause aspiration. So strategies that will continue will make you safe on this diet and liquid consistency. These are the possible risks and consequences if you choose to opt-out, but I can't make the choice for you. You have the right to determine your quality of life and I may disagree with it, but I need to honor what you want to do. So I really prefer to stay out of pushing them one direction or another, but give them all the facts and the explanation they need so they have the tools to decide for themselves what they can handle.

- [Amy] Wonderful, great, that's a really great explanation, thank you. All right, so we do have a few questions. Oh Angela, I just accidentally deleted your question so if you could please resubmit it, I apologize, I did not mean to do that. Laura is asking what are two to three published dysphagia assessments you would recommend?

- [Denise] The MASA is very detailed, Mann Assessment of Swallowing Ability. The SAFE, Deborah Ross-Swain published, was one of the authors of that. The nice thing about the SAFE is it comes with a manual of handouts, signage, so you don't have to reinvent the wheel. There's the BED, Bedside Evaluation of Dysphasia. So I think those are pretty standard assessments that have been out there. The MASA will give you severity of dysphagia and risk of aspiration based on the score, but for your patient to cooperate with those, they need to be able to follow directions. I am blanking on the one that I use, I think it's feeding and swallowing disorders. If you email me, and I can pass this on to Amy as well but there is a resource that helps you just evaluate by observing for the patient who can't cooperate or won't cooperate, so that you're just assessing what happens in the feeding process. But I like those particular options as far as dysphagia assessments, because again you have criteria that you can fall back on. This is why I scored it the way I did. That's the criteria, that's how many movements they were able to make in so many seconds. So the diadochokinetic rate.

And they have linked increased risk of aspiration from poor lingual range of motion. So we know there's a connection there.

- [Amy] Great, thank you. And then Ivy and Jean are both asking what language do you use in documentation instead of non-compliant? Do you have some better.

- [Denise] I like to say, yeah, I like to say the patient and or family has chosen to opt out of the recommendations or has chosen not to follow them. But I think if we know that they are an aspirator, I think we need to put in that they are a known aspirator, they've been educated, and the family has chosen to opt out rather than saying that they're not going to be compliant.

- [Amy] Okay great thank you, that helps. Shouldn't the drug food interaction effects be reviewed by the dietician? Is this in our scope of practice?

- [Denise] We need to keep in mind when we're seeing somebody living at home, they may not take these precautions seriously, so if we're seeing that they're consuming a banana and it doesn't work well with their medications, we need to make sure that they understand that. I like that booklet download, I think that really clarifies it, but I think for ourselves we can get that information and use it in our education of the patients and families. They may not recognize that this is a really big deal and it is.

- [Amy] Okay, so Angela is asking what do you recommend the SLP does when the physician decides to put his patient back on what patient wants, for example, mechanical soft or thin liquids. Do you document the physician has changed the diet, continue to follow?

- [Denise] Yeah, when a patient, yeah. When a patient starts to give us some flak about the diet, I can tell them well, you can talk to your doctor about options, many times

they will call the doctor and he'll put them on what they want, so patient and doctor agreed on a diet upgrade, so I think it's still my job to work with that patient to make the swallow stronger if they're willing to do that, but I also need to educate them on how to minimize the risk with that increased diet texture. So I think that's still part of our job to do that education, work on strategies, rather than immediately discharge them which can be seen as patient abandonment because they didn't follow through with what we said.

- [Amy] Okay, so Katherine is asking what are your legal professional options when the AFL staff refuses to comply with the therapeutic interventions? The director of a nursing home I know of had the doctor's RX changed from puree to mechanical soft diet because quote "no one eats pureed foods "so we just don't do it."

- [Denise] I think you need to pull up your documentation of what the patient is able to handle based on their dentition, based on their oral motor skills, and just do that education. Bottom line, you may have a hard time changing their opinion so it may be time, maybe this isn't the best facility because they're not following through with what you believe is medically appropriate. Sometimes you get in those positions where come hell or high water, they're not gonna do what you want them to do.

- [Amy] Okay, and we have a follow up question here. Do you recommend patients' families sign a waiver when they opt out of recommendations for diet texture?

- [Denise] No, no, no. And we're gonna talk about waivers next time in part two. There's a better way to go about it, so we'll talk about that.

- [Amy] Okay great, and then Kristen is asking to you tend to get palliative care involved for patients who decline, refuse your recommendation and who have known

significant dysphagia? They've been a good resource at her facility for these difficult cases.

- [Denise] Well when we take a look at, especially in the neurodegenerative disorders, there has been a lot of literature out there that recommends as soon as there's a diagnosis, they're involved in palliative care to allow the team to manage all the different medical problems. So they often have a lot of resources. So I will check all the resources.

- [Amy] Okay, and then James is asking on the last side you mentioned recording hearsay, what is meant by that?

- [Denise] You need to be careful when somebody says but this person told me, those type of things. What I get worried about, especially with chin tuck, is somebody has a friend of a friend of a friend that said oh, tuck your chin and you're gonna be fine. So we need to just try to document things that we truly know. The patient talked to the nurse or we talked to the families rather than third cousin removed, so just making sure that your documentation is clear and as honest as we can make it.

- [Amy] Okay great, and then one last question here from Maria. If we suspect premature spillage, is it enough to refer for an MBSS?

- [Denise] All right, again the standard practice of care, if you believe there is a pharyngeal component or the patient is at risk for a pharyngeal dysphagia, we would be doing an instrumental assessment, because what happens when it gets down there? With that premature spillage we have an open airway.

- [Amy] Okay, so that does bring us to the end of the questions. I do apologize that my Classroom is doing strange things today.

- [Denise] It's been that kind of a day.

- [Amy] I guess so, that's never happened before. But anyway, thank you so much Denise, this is a great part one, really looking forward to part two, this very very important information that you shared with us today, so thank you for that. And thanks to all of our participants for joining us today, we certainly do appreciate your time and look forward to seeing all of you soon, hopefully for part two. Have a great day everybody.

- [Denise] Bye bye.