Informed Consent: Continuing Dysphagia Treatment in the Midst of Recommendation Refusals — BLOG POST

By nicespeechlady.com / March 10, 2019

Another day, another set of dysphagia recommendations. Sometimes the recommendations are accepted, education provided, and it is smooth sailing. Sometimes the instrumental results aren't so well received and recommendations are not agreed upon by the patient. In this case, education is still provided, and at the same time, extra care is taken to document direct quotes from the patient or POA on decisions made. Specifics on recommendations and additional followup education is made in response to individual patient or POA comments, and facility protocols are followed-through upon regarding patient and POA choices as a result of informed consent.

In the case of not wanting to proceed with instrumental speech pathology recommendations, and if a patient desires treatment for rehabilitation of the swallow, what comes next? Does acceptance of recommendations have to come as a pre-cursor in order for treatment to be proceeded? I would argue no, although I will admit I didn't always feel this way. The purpose of this blog post is to provide reasoning for this position — if a patient is willing to participate in treatment, and factors are present that the patient is a candidate for treatment, even if they do not want to proceed with recommendations within the context of informed consent, I would maintain that proceeding with dysphagia treatment is the ethical thing to do.

Some SLPs I have run into professionally subscribe to the school of thought that due to liability issues, if a patient does not follow recommendations as outlined by an SLP, education is provided, paperwork is documented and then the patient is discharged from speech pathology care due to "non-compliance"— and treatment is discontinued. Treatment is stopped. I will say admittedly that in the past, I would cite liability as my reason for discharging a patient for not following recommendations. I would state: "It puts my license at-risk because it sends the message that I am acknowledging that their choice to not follow recommendations is acceptable by continuing to treat the patient." I would say that I would be at-risk for litigation and lawsuits if the patient were to have medical consequences from their decision to not follow the recommendations and still be under the care of an SLP. I stated in the past that if they are not willing to follow the safest recommendations for proceeding with rehabilitation, it would not be safe for myself to rehabilitate the patient.

This all changed one day when a more seasoned clinician gently challenged me about this. She brought up the issue of ethics. At first this didn't click for me, I didn't quite understand where she was coming from. However, as she explained to me, it is the patient's right to proceed with their medical decision to proceed with PO status, or not proceed with PO status. It is their medical decision to proceed with a certain consistency or not proceed with a certain consistency. It is also still their right to obtain rehabilitation services if they desire it if they are a candidate for it, independent of their decision for their acceptance of the medical decision for PO status, or a certain consistency. Having a hard and fast rule that if all recommendations are not accepted and followed-through upon, then patients will be discharged, is a pretty rigid position to take, she said. She also maintained that it might appear punitive. Instead, she encouraged me to consider taking each patient on a case-by-case basis, and not having an absolute that if a patient did not accept recommendations they will automatically be discharged from treatment and care that could result in rehabilitation of the swallow.

This really caused me to think.

She encouraged me to call ASHA and discuss this.

So I did.

I was advised of the same information. Take each patient on a case-by-case basis. The decision to continue treating or not continue treating will be based upon a host of factors, including: patient desire for treatment, patient abilities for participation in treatment, potential for improvement, prior level of function, etc. I have come to realize that discharging a patient should not be a card to play if a patient is not compliant with recommendations. Patients should be free to choose their course of PO status without fear of not having options for treatment.

There is a consensus in the field that there is informed consent for patient choices for how to proceed with their options for PO intake. What does not appear to be a clear consensus in the field is the SLPs role after a patient decides to not follow recommendations outlined by an SLP.

I would argue that I allowed fear to motivate my decision before to discharge patients for what I called non-compliance. We cannot let fear be a reason to deny a patient treatment for dysphagia if they desire it, and if other conditions exist that make the patient a candidate for treatment. If documentation is thorough and accurate, this should be effective in communicating the situation to protect our licenses if there were to be any potential litigious situations, if any.

In the medical model, if a physician were to advise a patient to take a medication, and the patient had a belief system that was a factor that resulted in them deciding to not proceed with taking this medication, it would not be prudent for physicians to drop the patient if there is not compliance with all medications or treatments prescribed. Patient's have rights and self-determination to choices for their health care.

I do not have the data on what percentage of medical speech pathologists currently subscribe to the philosophy of automatically discharging patients from care if recommendations for safe swallowing are not followed-through upon; however, there are speech pathologists that do proceed with this in their decisions on a daily basis.

I would like to complete this blog by speaking about a patient of mine who I will call John. John has a serious neurological condition that globally impacts his body. His condition is deteriorating and advancing over time. Ten years ago, he was recommended to be NPO after a video swallow assessment, and was recommended to initiate alternative means of feeding. He refused. He was not allowed treatment at that time for dysphagia as a result of refusing the peg tube and deciding to continue PO status. Fast forward to ten years later, I met John when he became my patient in home health. He has not experienced one bout of pneumonia. He has severe coughing episodes, but has not experienced choking episodes. I started providing treatment to him, although the official recommendation for NPO still remains. In understanding that this is the official recommendation, tertiary recommendations have been given, such as utilizing gel thickeners, presenting liquids via spoon, chewing on one side of the mouth over the other, etc., have greatly reduced his clinically overt sign/symptoms of aspiration — although they will likely never be fully eliminated. Also, a feeding tube would not have completely eliminated this risk, either. Oral motor exercises have greatly assisted his swallowing patterns. He is using other compensatory strategies that are helpful. If I had continued to subscribe to my previous philosophy that he could only receive dysphagia treatment if he followed recommendations to be NPO, he would not be benefitting from other outcomes from treatment. This treatment he is receiving now, he should have received ten years ago, and he could have received a reduction of symptoms for the past ten years. He had a right to this treatment.

In conclusion, I had almost forgotten that I had previously subscribed to the philosophy that recommendations had to be followed for treatment to be proceeded with — until I came across an SLP this week that communicated this very belief system.

We need to discuss this as a field, and remind ourselves that if we truly say that a patient has a right to choose consistencies or PO status, they should also be free to receive the treatment they desire in the context of that decision.