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ICF Framework and Narrative-Based Interventions:  
Lessons from a Care Provider Turned Cancer Patient  
Recorded August 13, 2019

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SpeechPathology.com Course #8995

- [Amy] And at this time it is a pleasure to introduce Janelle Lamontagne this afternoon who is presenting the ICF framework and narrative-based interventions, lessons learned from a care provider turned cancer patient. Janelle is a medical speech language pathologist who serves adults in adult care, rehabilitation and palliation. After being diagnosed with a malignant brain tumor, she has been investigating the importance of narrative-based practices as a means of providing holistic client-centered care to clients with terminal diagnoses. So welcome Janelle, thank you so much for joining us today.

- [Janelle] Thank you Amy. So good afternoon everyone. Like Amy said, my name is Janelle. I am gonna apologize ahead of time, I came down with a cold a couple of days ago so I may suddenly disappear for a second to take a drink of water, but I will try to keep this rolling as best I can. So today I will be speaking about the international classification of functioning framework, evidence based practice and narrative-based assessment and interventions. So just some housekeeping items, as for copyright and permissions, the Bloom's Taxonomy graphic that I'll be showing you a little bit later is released under Creative Commons Attribution license and attributed to the Vanderbilt University Center for Teaching and all the photographs are owned by myself. So I have been working at Brandon Regional Health Center in Brandon, Manitoba since 2013 as a part of a team of three SLPs. And I'm fortunate that I've been able to follow my patients across their entire continuum of care. So we service the three of us 300 plus beds, we go to adult psychiatry, geriatric psychiatry, the emergency department, ICU, acute care and surgery, palliative care, rehabilitation, as well as waiting placement supportive care and chronic care. Now when I list all those areas, the reason I do that is because we have a really unique set up and that the same SLP, we'll follow the patient across all floors. So I may initially see a patient in the emergency department and then they end up in the ICU and then they end up in rehab. So I follow them across all those

areas, which gives me a really unique opportunity to get to know them. So because of that opportunity, I have been beside my patients while they receive life changing diagnosis and also have made really difficult life changing decisions. So while that is one of the reasons I am doing this presentation, I also have a very personal reason for being passionate about narrative-based practice. Two years ago, my life took a very drastic turn when I went from being the healthcare provider to the patient. So why the interest in narrative-based practice? Well, on May 10th, 2017, I was unexpectedly diagnosed with a cancerous brain tumor, a grade three anaplastic astrocytoma and was told that I had three to five years to live. Now when I say unexpectedly diagnosed, I really mean it. I had zero symptoms and I won't go into the whole series of events that led to the diagnosis because that would take way too long. But let me just say that if it was on Grey's Anatomy, no one would believe it. They would think it was too farfetched.

So, as you can see in my picture of my MRI, that is my actual brain. The tumor is located in the premotor cortex of my left frontal lobe right next to Broca's area. So as an SLP, initially all I could think was really of all the locations it had to be there. Why couldn't it be in the occipital lobe or even in the parietal that would be a little bit better rather than right in the area that controlled speech language. So the picture on the left of your screen is actually the morning I went in for my surgery and that was within a month of the diagnosis. I had met with my neurosurgeon and he didn't have to twist my arm when he recommended that we do an awake craniotomy to monitor my speech and the movement in my right arm and the right side of my face. So on June 29th, 2017, I underwent a 10 hour awake craniotomy and here's the picture taken about 12 hours post-surgery. So I was very fortunate that I had a nice surgeon who decided to only shave the part of my head he had to. I ended up with 29 staples in the shape of a horseshoe. On the MRI picture, again, you can see where it was removed. They got pretty clear margins. So since my operation, I have undergone six weeks of daily radiation therapy concurrent with low dose chemotherapy, which was followed by 12

rounds of high dose chemotherapy. I actually finished my last round of chemo, the end of October, this past October. Throughout this whole process, I was struck with the question, how do people with no medical background get through this? When you were diagnosed with cancer or any other life threatening disease, you instantly go into survival mode. You stop processing nearly everything other than your fear and your grief, your life is completely upended and everything to be normal is gone in a flash. Your diagnosis, along with the subsequent treatments manifest themselves in so many physical and psychosocial ways and unfortunately traditional medicine and traditional therapy do a pretty poor job of addressing these areas. So without further ado, let's brainstorm. No pun intended, what we as a profession can do to change that. So here are my objectives for this presentation. By the end, we should be able to describe the role of the international classification of functioning framework and evidence based practice and assessment and intervention planning.

Explain the importance of incorporating narrative-based practice in the assessment of clients within the medical setting and discuss ways in which narrative-based practice can be used to provide holistic client centered care. So speech language pathologists are to use the international classification of functioning framework in our assessment and planning intervention. The ICF provides a holistic way of evaluating and supporting a person's functioning in real life situations. It provides a framework for the SLP to consider more than just the obvious communication disorders. When using the ICF, the SLP begins by identifying body functions that are impaired. Then if possible, body structures that might account for the impairments and functions are identified. Next, the SLP evaluates how these impairments limit a client's ability to carry out specific tasks, particularly those measured by standardized assessments. Frequently, assessments and intervention for communication stop at this level. The SLP is asking if the client has or does not have the capacity to do a task. The ICF however, also considers how the communication impairments may restrict the client's ability to perform actual tasks in real life activities and participate in a variety of social activities.

Many factors beyond the presence of an actual communication impairment may influence a client's performance and participation. Because of the limitations of standardized testing, a communication deficit may not manifest in speech, vocabulary, syntax or conversation with the clinician in a structured situation. Yet it may manifest itself in more challenging life situations. Additionally, other contextual factors may influence performance and participation. So these contextual factors can be of two different types, personal and environmental.

So personal factors can include other symptoms or deficits related to the health condition beyond the communication disorder. So, for example exhaustion or nausea, comorbid health conditions such as diabetes and psychosocial factors such as fear of the disease, depression, sense of loss, financial worries. Environmental factors can include the available support of family and friends, the attitudes of those family and friends and services and policies related to the actual healthcare system. Gathering information regarding performance, participation and the contextual factors influencing that performance and participation requires allowing persons to tell their stories in interviews. I'm gonna use myself as a case study throughout this whole presentation. So let's quickly look at the ICF in terms of my case. So my health condition is cancer.

My body functions and structures impacted is my left frontal lobe of my brain. My activities that are impacted are my career, my social life, my ability to volunteer, even activities such as getting groceries were impacted at one point. My participation, it was greatly reduced in all those activities and really in life in general. The environmental factors, which greatly impacted me was that my family lives in a different province. My neurosurgeon, radiation oncologist and medical oncologist are all in Winnipeg, which is a two plus hour drive away, which means I made four hour round trips for every treatment. Both my brain tumor and young adult support groups were based out of Winnipeg as well. It was very isolating living here because it's a smaller rural facility and didn't have as many resources available. The personal factors which influenced my

functioning and to an extent still do and probably always will are chronic fatigue, nausea. And since my diagnosis and surgery, I have struggled with anxiety, depression and post traumatic stress disorder from the surgery itself. It's not very fun, too happy or skull sawed and drilled while you are wide awake. So I blame a lot of my anxiety and depression on the fact that my frontal lobe was played with while I was awake. But research actually shows that the incidence of PTSD in cancer patients, which is one in five, is similar to that of combat veterans. So now I'm going to move on to evidence based practice. We are going to take a deeper look at each part of the triad that forms EBP. So as we all know, good research is invaluable. It should form the foundation of everything that we do as SLPs. If we don't stay up to date on research, we really have no business practicing. That being said, when we think about research, we have a tendency to think about what is quantifiable. We tend to equate research with graphs, statistics and measurable results. So doing x intervention with y population should result in z outcome.

While quantitative research is invaluable, it sometimes isn't necessarily practical when working in certain settings or with certain patients. So I don't even have to have you guys raise your hands to know this answer, but have any of you ever had a textbook patient? I've worked with hundreds and hundreds of clients and have yet to meet one that follows all the rules. Due to core morbidities, our patients often do not meet the checklists of the experimental groups and research. Therefore, even meta analysis, the gold standards of research don't necessarily 100% apply to our patients. If research evidence was the be all and end-all to assessment and intervention, we as clinicians would be out of work. A well-designed task analysis of assessment and treatment could pretty much do our jobs for us. So since I have used myself as a case study, let's look at the research evidence for patients and patients with brain tumors. The majority of the literature on brain tumors and speech language pathology focuses on types of brain tumors, characteristics of related speech and language impairment and strategies for addressing the impairments. However, brain tumors may cause a wide range of

neurological dysfunctions including aphasia, but the treatment strategy for this population is still understudied. Furthermore, cancer related language disorders are considered secondary to brain cancer in the medical field and therefore are undertreated. Just a little side note, I'm really excited that there's starting to be more information out there on the way chemo brain affects patients and what the role of the SLP actually is in that population because that's something that I feel hasn't really been looked at. I'm currently taking , 32 hour course conference right now and it has some really good information on treating cancer patients. Just a little FYI. So all the research evidence that I just shared focuses on the assessment and treatment of language disorders in patients with brain tumors. But what about the psychosocial support? In a meta analysis of over 6,000 articles on treatment of brain tumors, Ford and colleagues reported that only 1% addressed the broader psychosocial needs of the patient and the family. So that's a little bit just heartening.

So now let's move on to the second piece of evidence based practice, clinical expertise. So as SLPs, we require a masters degree to practice. When we look at Bloom's Taxonomy, we should at minimum be at the second level from the top. So evaluate and our justification shouldn't just be, well, I read this article ones or the podcast told me to do it. Full disclosure, I'm obsessed with podcasts and annoy the people around me by quoting them daily. But that's besides the point, I don't want you guys to think I'm just bashing podcast because I love them, but we need to critically think a little bit more. As clinicians, we have the responsibility to take the case history and prior medical history of our patients, talk to our patients about their goals, analyze our mental library of knowledge pertaining to this situation, which includes previous experiences with similar populations and be able to justify why we are doing what we are doing. All of these factors converge into clinical expertise. So my example of how this pertains to my case is a little different this time as it actually is in regards to my neurosurgeon's clinical expertise. As I was asymptomatic at the time of diagnosis, much of the research evidence would suggest a wait and watch treatment approach.

Wait until I start having seizures, migraines, cognitive decline or motor problems before offering surgery. Brain surgery is always risky, so the wait and watch approach is a conservative treatment plan. However, when my surgeon looked at my overall health, the location and size of the tumor and my age, he suggested surgery and possible chemo and radiation right away. He then told me that he would recommend an awake craniotomy in the intraoperative MRI suite so that he could be more aggressive as they would be able to monitor my speech, language and motor movement.

Throughout the whole appointment, he provided research evidence that used his own clinical expertise to justify his suggestions and develop an operative plans specific to me. Now let's look at the third section of the triad and the one I'm the most passionate about. So I've touched on this a little bit already, but the third part is client values. What matters to the client? This should be one of the first questions that any patient is asked after a diagnosis. What matters to you? However, this piece is often missed in healthcare or seen as less important than research evidence and clinical expertise. As SLPs, we pride ourselves on helping people communicate, giving them a voice and helping them regain their voice. Sometimes though we are really bad at listening to what they want to tell us.

As a whole, healthcare professionals tend to focus more on their own agendas and goals for the patient than the goals of the patient himself. As a patient and a healthcare provider, I was able to advocate for my values throughout my journey that many of our patients either don't have knowledge of the healthcare system or are too intimidated to speak up for themselves, so their values may be dismissed. Well, how can we change that? Before we get into it, let's go back and see how the international classification of functioning and evidence based practice converge. Because that joining will guide us into narrative-based practice. So just to review the World Health Organization international classification of functioning, begins to look at functioning in terms of diagnoses and affected body structures and the impact they have on a person's

activities and participation. It then investigates the environmental factors and personal factors that influence participation. We then have evidence based practice. So I know this might look a little bit confusing, but I will do my best to explain how I see it anyways. In looking at evidence based practice, each piece corresponds with a certain amount of ICF. So current research pertains to the health condition, the body functions and structures and activities. So for example, in my case, research would be geared towards brain cancer, the areas of the brain impacted and what impact the affected areas have on certain tasks. The current research would hopefully also provide information on treatments to improve those tasks. Client values looks at participation, environmental factors and personal factors. So as a patient I just wanna get better and be able to participate in my life fully. I need people to recognize the limiting factors though.

Anxiety, depression, PTSD, fatigue, nausea, finances, family support and access to additional psychosocial supports. And lastly, all components of the ICF should be integrated by our clinical expertise. So now that we have an understanding of how the ICF and evidence based practice come together, let's discuss how we can use narrative-based practice to assess our patients in a way that uses both. So what is a narrative? According to the dictionary, a narrative is a way of presenting or understanding a situation or series of events that reflects and promotes a particular point of view or set of values. So when I read this definition, a few key words stick out to me. Understanding, events and values. Narratives are the stories we tell ourselves and others based upon our values and our understanding of certain events that occur. So let me give you a simple scenario to highlight this. So pretend you're driving to work one morning and this other vehicle come speeding up behind you and then pulls in front of you and proceeds to cut you off, your knee jerk or my knee jerk reaction may be to think, look at that person, she just cut me off. She obviously has no care for her safety or the safety of others. Maybe she should've left her house earlier this morning if she's in such a rush. That would be my narrative of the situation. The driver's narrative

however, may be that her three year old just fell off the play structure at daycare and is being taken by ambulance to the hospital and she needs to get there as fast as she can. She may even be completely unaware that she was speeding or that she even cut you off. So I just wanted to tell that story or give that example to illustrate the fact that narratives are subjective based upon your knowledge, your ideals and your interpretations of what is presented to you. There is increasing awareness of the value of narrative-based practice in client centered care and speech language pathology.

So narrative-based practices in which SLPs listened to clients personal narratives of their lived experiences enable SLPs to gain an understanding of factors that influence a client's performance and participation in the real life setting and to develop intervention programs that consider the needs and values expressed by the clients.

Narrative-based practice can really seem quite daunting in terms of time management. However, it can lead to better or functional outcomes in a shorter period of time. The easiest way to incorporate narrative-based practice into assessment is through obtaining your case history.

This doesn't replace the need for a thorough chart review as the the patient's perspectives and knowledge of their medical histories may differ greatly from the medical teams, but it will provide you with a lot of insight into what parts of the patient's medical situation are the most important to him or her. Furthermore, you will learn the areas of rehab the patient is actually interested in. So this is where I want to segue and to something else that I'm very passionate about and it's a problem I've seen occur more times than I would like to admit since I've been working. So in the past I've had patients, as I'm sure some of you have also had that were labeled as noncompliant by the medical team. In most cases, the noncompliance could be categorized in one of two ways. First, the patient didn't listen to the plan of care or second, the patient was viewed as unmotivated. Sometimes this perceived noncompliance and lack of motivation results in patients not receiving the best of care

from their medical team and this is heartbreaking. We are letting our egos get in the way of providing quality care. We, and I am using the word we to represent the medical team in its entirety, not just SLPs, are often forgetting a key piece of the puzzle, patient autonomy. So one of the ways I want to look at it is or I try to look at it is that as long as they have all the information, everyone has the right to make what I perceive is a bad decision. It can be so easy to get caught up in, well, they're not participating in therapy the way that they should be, so they're not motivated, they don't want to get better. Well, what are we doing in therapy that they find un motivating? We shouldn't be doing anything in therapy that the patient doesn't find motivating. So to give you another example, I myself have made so many perceived bad decisions since my diagnosis.

I went to a music festival the day after my 29 staples were removed from my head. I've put myself at risk of infection by getting multiple tattoos since diagnosis. I've traveled extensively across Canada and the US, everywhere from Niagara Falls to Las Vegas to San Francisco to Newfoundland to Boston, all with a compromised immune system. I even did a road trip from Saskatchewan to New Mexico while I was on chemo. I went back to work one month after completing my chemo. So why was I so noncompliant? Why was I willing to compromise my health in so many different ways? Well, these pictures on the screen, these memories that I've made far outweigh the risks for me. And fortunately, I've had a medical team that not only respected but supported my choices.

So my medical team asked me the key question that I would really like to be, if you take anything from this presentation, I would like you to remember this question. What matters to you? My medical team asked me that question and that had a tremendous impact on my journey. So now let's discuss additional questions that are important to ask in narrative-based practice. So one of the ways of obtaining information for narrative-based practice is simply through ethnographic interviewing. Ethnographic

interviewing, there's a lot of information out there on it. I'm just going to highlight some of the questions and types of questions that I find the most useful. So first of all, there are five types of descriptive questions. The first is grand tour questions, which are intended to encourage a person to talk about their broad experiences. They tend to ask a person to generalize how things usually are. So for example, tell me about a typical day with your family. That would be a grand tour question. Mini tour questions are same as grand, but they ask the person to describe a specific activity or event. They usually follow responses to grand tour questions.

So for example, you mentioned that you like to go on family outings in the afternoon, can you describe an outing that you've gone on? So it relates to the grand tour question, but it just gets a little bit more specific. Example questions are more specific than both of the tour questions. They take some idea or experience and ask for an example. So, for example, if the patient says, I'm just not myself anymore, you could say, look, give me an example of what the old you used to do. Experience questions, so they ask about experiences in a particular setting. So tell me about some of your experiences with your oncologist. Experience questions tend to get at those atypical occurrences.

So you will get the extremes, either good or bad. Consequently they are best asked after numerous grand tour and mini tour questions so that you as the interviewer have information you need about what are typical behaviors, so you're not under the assumption that this atypical experience is the norm. And lastly is native language questions. So in medicine and in speech language pathology, there's a lot of jargon and we just wanna make sure that we understand how people are using words and that people understand how interviewers and other professionals are using the same words. So native language questions are useful for these purposes. They ask people to use the terms and phrases they would most commonly use and then allow us to understand what these terms mean to the person. So, for example, you said you don't

want palliative care, what does the word palliative mean to you? A lot of people believe that palliative care means that you're imminently dying. And as soon as that P word is brought up that there's no hope, basically the medical team has given up on you. And that is not at all the case. Palliative care is more for quality of life and symptom management than anything. I'd like to give an example of... That's from where I work. So our hospital is divided into the general center and the ascena bland center. Now, one floor of the ascena bland center is actually our palliative floor. So the floor below it, however, is our rehab floor.

So after people are medically stable in the general center, they will be transferred over to the ascena bland center for rehab. We have to be very careful when we say that they're going over to the ascena bland center because it's a small community and nearly everyone who is a patient has known somebody that goes over to the ascena bland center on the palliative floor. So we really have to be cognizant of, we might just think nothing of saying, okay, we're gonna transfer you over to the ascena bland center and the patient may hear, oh you're transferring me over to palliative, that means I'm dying. So that's just a simple example of why it's so important to look at what people's interpretations are of certain words and certain phrases. So another type of question for ethnographic interviewing are structural questions. There are lots of different types.

Again, I'm just going to briefly highlight them. The first is strict inclusion. So X is a kind of Y. So what kind of things did the doctor say that would be an example of a strict inclusion question? Spatial, X is a part of Y. So what are the steps to your treatment regimen or what are the... What steps do you go through every time you go for chemo? That would be a spatial question. Cause and effect, X is a cause of Y. So what things are causing you to feel depressed? What have been the results of telling your family how you feel? Those are example of cause effect questions and I didn't say it at the beginning of this section, but these will get you to more of the bones of what the person's thinking and what they're feeling because they require a specific answer.

Rationale, X is a reason for doing Y. So what are your main reasons for wanting to come down to therapy? That's an example of a question. Or what are your main reasons for skipping, skipping physio today? The next one is location for action. So X is a place for doing Y. Where are the places that you like to spend time with your friends? Where are the places that you feel most comfortable? Function X is used for Y. What items do you use to make eating easier? Means end, so X is a way to do Y. What are the ways to inform your family how you are doing or what are the ways to keep you from getting sick? What can we do to help A, B and C get better?

Second last one, sequence. X is a step or a stage in Y. What are your steps for getting ready in the morning? And the last one is attribution, X is an attribute of Y. What are the attributes of the people who have been the most helpful for you? So there are lots of different questions that can come from these formulas. I just gave one or two examples for each type, but they are limitless. I'm just gonna pause here for a second and mute my mic while I take a quick drink. Okay, now to move on. So asking the right questions. Not all questions are created equal. There's a fine line between interviewing a patient and interrogating a patient. While we want to obtain as much information as possible, it is important not to ask too many questions and not to ask multiple questions at a time. When interviewing a patient, it is helpful to start broad by asking questions such as what does a typical day look like for you or how has your life changed since you were diagnosed with cancer?

Based upon the answers you are given, you can show the patient that you are listening attentively by restating a theme that they have mentioned and probing further into that topic. So for example, you mentioned that you haven't been able to work, how has that affected you? Since my diagnosis, I have been seeing a psychosocial oncology clinician and he has been really good at asking me the right questions and as an SLP I like to think that I know where people are going when they start asking me questions and what their agenda is, but he's caught me off guard several times. He has picked

out themes in my thoughts and behaviors that I was completely oblivious to. I remember one particular session where I struggling with my prognosis of three to five years and I was telling him about how I felt it was difficult to find the balance between pessimism, realism and optimism. I felt that if I accepted my prognosis then I might as well just give up then and there. He asked me a question that I will never forget. What does hope mean to you? I hadn't even realized that our whole discussion up until that point surrounded the concept of hope and my fear to hope for a future. If he hadn't been listening for a theme in what I was saying, I'm not sure how the session would have ended up and I'm not sure that mentally and emotionally I would be in the place that I'm in today.

So by starting broad and restating and probing certain themes, the information you can obtain during your interview is limitless. It is important to remember however, that silence is also a very powerful tool. We have to allow our patients time to process our questions and formulate their responses, especially when we are dealing with the patients who have been given really bad information or diagnoses or are going through chemotherapy and radiation. I know for myself, my processing, if it were tested right after I was diagnosed, I would have been in trouble because I wasn't processing things as quickly.

Your mind has so much going through it that it kind of weeds out what it seems to think is less important. And so we really have to give that extra time to allow them to consider our questions and form their responses. Also, the nice thing about silence is that sometimes it makes people uncomfortable and it will give people the urge to break the silence and we can use that to our advantage as well. Now that we've discussed some of the types of questions to ask, I'd like to provide just some words of caution. So first, listen to learn not to judge. Our foremost priority should always be our patients well being. Our intervention choices should never be colored by our personal biases. When we are asking for people's narratives, sometimes we find information out about

them that isn't... Everyone has their own bad parts of their life and things that aren't necessarily socially appropriate and our patients are no different. So sometimes we'll find out things about a patient that could potentially color our judgment of their character and we should never allow that to affect our treatment and our therapy and our approach to providing them the best intervention possible. Secondly, avoid why questions. Why questions can come off really harsh and critical. So instead of asking your patient why she feels a certain way, because that can... Just to highlight the example of, well, why do you feel sad? That came across very uncaring and critical. Instead, I could say, so what has caused you to feel that way?

That's taking the point of the question off of her and on to this other what? So what has caused you, not why do you feel that way. Third, we should never ask questions just because we're interested. Information that is obtained should be need to know and assessment or intervention based. Sometimes patients just really need to talk to somebody and you'll be that person and you'll learn more information than needed and that's okay, but we shouldn't go fishing for information just out of curiosity sake. And fourth, when dealing with people in vulnerable, emotional states, it is important that we remember our scope of practice. As empathetic care providers, it can be so tempting to try to fix things by giving advice. However, we must be cognizant of our roles and make the appropriate referrals to other team members as needed. I know I personally am on the phone with our social worker, pretty much weekly just to have them help out with those areas.

So now that we've discussed what types of questions to ask, I'd like to use myself again, you're gonna think I'm very egotistical, but use what you know. I'd like to use myself as a case study to show the potential differences between the narrative of a medical team and the narrative of a patient. So here is something that could be pulled right out of my medical chart and this is the narrative that my medical team would have. So I am a 31 year old female with the prior medical history of acquired Von

Willebrand disease, which is a bleeding disorder. I was diagnosed with a grade three anaplastic astrocytoma in 2017 at the age of 29. I had a debulking craniotomy June of 2017, followed by 12, oh sorry, followed by 30 radiation treatments concurrent with low-dose temozolomide which is a type of chemotherapy. And then that was followed by subsequent high dose chemotherapy for 12 months, monitored by three month MRIs which have remained stable and my overall prognosis that I was given was three to five years. So that is the medical team's narrative. And here is my story. While I'm sharing this, I would like you all to pay attention to the differences between the narrative of the healthcare team versus my narrative. And I'm going to share this story as if I were the person who was asked the right questions. So here's a little background information. I have a rare severe bleeding disorder called acquired Von Willebrand disease. Basically, my blood doesn't call it on its own. Seriously, the machine's doing the testing timeout before my blood clots. On April 29th, 2017, I randomly had a vein rupture in my upper arm.

Because of my bleeding disorder, I ended up in the ER for treatment. I reacted to the treatment and ended up back in the ER four days later with a severe migraine. Because I had just had this spontaneous vein rupture, my hematologist was concerned about a brain hemorrhage in order to CT scan, boom, brain tumor. I was 100% asymptomatic. So everything felt so surreal. How did I have a golf ball sized tumor in my head and not know it? Especially in that area, the area of the premotor cortex and Broca's area. I was told at that point in time it was likely low grade and I should be fine once it was removed, I shouldn't require any chemotherapy or radiation and that it was likely benign.

So a few appointments and MRIs later, I was in for a 10 hour awake craniotomy. Honestly, I don't remember anything from the time I was diagnosed until my surgery. It's just a big blank. I must've just went through the motions. I know I went to work until June 23rd because I have reports I wrote during that time. I'm not sure how accurate

they are, but I know I worked right until up to six days before surgery. But I have zero recollection of that time. I think it was just processing. Back to my brain surgery, for the surgery, I was given IV sedation, like when you go to the dentist and local freezing to my scalp. I remember the sounds of my head being bolted to the table. I remember the feeling and the noise of the bore holes being drilled and my skull being sawed. Like I said earlier, to this day, I have PTSD from that. I saw a psychologist for exposure therapy, which has helped dramatically because now I no longer have a panic attack or feel like I'm going to be sick when I hear sawing or drilling. When I first came back to work after 18 months off, of course they were doing renovations on floors.

So there were several times where I had to hurry up and leave a floor as soon as I heard a drill or a saw turn on because I was going to either burst into tears or pass out. That's much better, but I still don't enjoy those sounds and they still make me feel quite sick. The rest of my surgery consisted of the surgical team mapping my brain. So I was connected to all sorts of electrodes and was asked to speak and move my right arm throughout the operation so that everything could be monitored. I had actually told my neurosurgeon that I didn't care if my arm became paralyzed during the surgery as long as he got the whole tumor. So I didn't tell him when I could feel him probing the area that controlled my arm.

The electrodes on my arm gave me away though and he... I don't know if any of you watch the Show House and how all patients lie, but that is what my neurosurgeon said as he's working on my brain to the resident is see patients lie, I was affecting her arm. We talked about politics, work, you name it. At the point where they asked me about work and I said, oh, I do video fluoroscopic swallow studies quite often, they decided that they didn't really have to worry about my speech that much longer. 10 hours later my head was stapled shut and I was taken to the recovery room. So despite neuro checks every hour throughout the night, I felt great the next morning and I'm not exaggerating at all. Like I actually said the next day, oh, I don't think I'll have to be off

work for six weeks, I think I can go back next week. Little did I know. I thought I had come out of surgery with no deficits. Well, that was until I tried to send my first text. That was the moment that I realized that I had right neglect and apraxia in my right hand. So these deficits became increasingly apparent when I no longer was even able to print my name and I lost my cutlery at every meal. I nearly shoplifted as well once I got home because we went to get groceries, my mom and I and I picked up a couple of things in my right hand, completely forgot about that then went to leave the store. I don't think they... I don't know that brain surgery would have been a good excuse if I were to be caught, but luckily my mom caught me before I had to find out. Four days post-surgery, I was discharged home.

The next three weeks following my surgery went really well. I was sure that the tumor was gone and that life would resume to normal. I just had to wait the required four weeks before returning to work. I spent time at the lake and I joked about how lucky I was to have a month off in the summer. Then I got the call that my neuro surgeon wanted to meet with me. What followed were words such as cancer, chemotherapy, radiation, life expectancy, fertility preservation, et cetera. I remember crying the entire two and a half hour drive home from the hospital and pretty much every day after that for a while. I would fluctuate between anger and sadness and apathy daily. At times I thought, what's even the point of treatment? I'll be dead in three years anyways, but I proceeded.

Two weeks later, treatment started. Brandon wasn't able to offer the type of radiation treatment I needed, so I made the five hour round trip to Winnipeg every day for six weeks. My hair fell out and I had radiation burn on my scalp. I'm so lucky that I didn't experience some of the headaches that other people do, but my fatigue was awful. It felt like with every step I took, I was dragging around 100 pound weighted blanket. Chemo also kicked my butt. I had five days of treatment, followed by 23 days off for 12 months. I needed platelet transfusions and ended up in the hospital for IV hydration.

One of the hardest things about chemo was that I was off work and so I had five days of chemo, which I felt horrendous. And then the following week I would start feeling a bit better and I have one week of nearly normal and then it was start over again. And during this time I really felt... During that one good week, I really felt a loss of identity. If I wasn't an SLP, what was I, what was my purpose? I had just gone to school for six years to become a speech pathologist, I didn't know anything else and now that's taken from me. So what am I supposed to do with my life? I needed something. So I began fostering puppies for the Humane Society. I already was a foster failure with my first dog, so I should've known I'd end up keeping another, but I think my stats are overall pretty good. I've only kept two out of seven. I finished chemo the end of October, 2019.

Sorry guys, my computer just logged out, so I'm hoping you can still hear me. Great, perfect. Where was I? I finished chemo the end of 20... I can see the PowerPoint now. It's all good. I finished chemo the end of October, 2018 and throughout that whole process, my goal was to return to work. So I rushed back within a month of treatment and that's when I crashed. All of this stress and anguish and pain of what I had gone through hit me. I couldn't function. So that's when I actually started seeing a psychologist to help me process and grieve everything that I'd been through. I am now in a much better place and I'm so happy and fortunate to be back to work full time. That being said, it has been very emotionally taxing to work with other cancer patients or those with terminal diagnoses. However, I also find it so very rewarding because I feel like I have a unique perspective. I've been given a glimpse into the other side. So that brings us up to this moment. So why did I just tell you all this? I shared my story because narrative stories are important. In order to relate to our patients and provide the best services possible, they have to feel like they can speak to us. So I'd like to share a quote from Brene Brown. "We're wired for story. "In a culture of scarcity and perfectionism, "there's a surprisingly simple reason we want to own, "integrate and share our stories of struggle. "We do this because we feel the most alive "when we are

connecting with others and being brave with our stories." I know that in my case, as a patient, telling my story has been freeing. It also can be very scary and the amount of vulnerability you feel when you tell your story can be overwhelming. But it has helped me tremendously come to terms with everything and helped me move forward. And I truly believe 100% that we need to offer our patients that opportunity as well. So as a health care provider, hearing the stories of patients allows me to connect, empathize and find meaning in their actions. So as I'm sure you could see from my narrative, my hospital records leave a lot out. They leave out the decision, the struggle I went through when I had to decide in less than 24 hours whether I was going to preserve my fertility and in doing so delay my cancer treatment.

They left out how hard it was to tell my little brother and my little sister my prognosis and they left out the guilt of being a patient and the guilt of what you're putting your family through. I know it's completely irrational, but that is a very real part of being a patient. And when I look back at how I practiced prior to being a patient myself, I think of all the times I told patients when they were struggling, just lean on your family, your family wants to be there to support you and I could just slap myself because that's the last thing you need to hear as a patient. You are feeling so much guilt and that's really not a helpful answer. Okay, so let's discuss the ways we can use narratives in therapy. So narrative-based practice is essential to providing holistic client centered care. We need to treat the patient, not just the disease. Narrative-based practice informs us of client values and guides us into establishing treatment goals, addressing participation and functioning in daily activities. Furthermore, listening to patient's stories provides us with insight into environmental, psychosocial and motivational barriers to success. Because client goals are so personal and individual, it is impossible to provide you with specific tasks that can be used with all patients. But I can give you some activities that I as the patient would find meaningful were my ability to communicate be limited. So these include brainstorm a bucket list. What are the things the person wants to do before it's their time to go? Recall the names of family members and friends, formulate

lists of questions for health care providers. And this is one that I think is very important because in my experience it is really difficult to remember everything you want to ask your doctor in certain appointments. So it's really important to have that list of questions and if we have this therapists can help them formulate them, that's huge. Script important conversations with friends and family. Develop outlines for a memoir. Voice or video record special memories. Plan their legacy and describe the occasions behind family photos. These are just the tip of the iceberg. There are so many other ways we can incorporate narrative-based practice into intervention. We just have to be willing to take the time to listen to our patients.

So here are some therapy ideas guided by narrative-based practice. So you could facilitate active participation in life. So help organize an anniversary supper, help sequence steps to go bowling. That's actually something that I've recently done with a patient is that was his goal, when he goes home is he wants to be able to go bowling again. So we've been sequencing what you need to do to go bowling. Practice calling up to invite a friend to visit. We want to make sure that we are allowing our patients to participate as fully as possible in their lives. Follow a recipe to bake a birthday cake, identify factors limiting participation and brainstorm solutions. Okay, I'm just gonna take another drink right now, so I'm gonna mute my...

Sorry about that. I can feel my throat becoming more scratchy as we go along. And one of the things we can do is just go through and ask the patient, okay, what are some of the things that are limiting your participation? What are some of the things that are making it hard on life and find different solutions because sometimes I've noticed that patients get caught up in a, well, I can't do this anymore and I can't do that anymore, but there are actually solutions to help them. We just need to think outside the box a little bit. I'd like to give you an example of where I've actually used the questions, what matters to you with patients and how I've incorporated their answers into therapy. And so, the first example I'd like to give is for a patient that ended up in

the ICU for quite a while. She had respiratory failure, had a really difficult time being weaned off the ventilator. She was just kinda multi organ failure, septic, just all around a very unhealthy person by no fault of her own. And she was always this very spunky lady and I could always count on her every day when I went to see her to give me a laugh, she was feisty. At one point when I was first assessing her, I asked her if I could take her teeth out to clean them before we did the swallow assessment and I didn't realize that she still had her own teeth and she's like, well, that would be quite nasty of you. So that was the type of personality she was and that's the lady that I was expecting this one day when I walked into her room. And what I found was her sobbing and just completely distraught because she felt so ill and it felt so ill for so long. And she just kept saying, you know, I'm just done, I just wanna die, I can't do this anymore.

And I tried to console her as much as I could and I wasn't getting anywhere. So finally I asked her, I was, I know I should have asked it sooner, but I find that I asked her, I was like okay, what matters to you? And she instantly said, "My husband, "he's such a good man and he has dementia "and it's not fair that he has dementia. "And right now he doesn't know where I am "and he doesn't know what's going on and he will be so scared and I worry about him." So from then on I said, okay, well, where is your husband? And it turned out that he was actually in our center for geriatric psychiatry because she was the caregiver and when she was hospitalized, there was no one able to take care of him at home.

So as therapy that day, once we got through everything, we wrote a note for her husband. She had macular degeneration, so she dictated and I wrote it for her and that was our therapy, was writing a note to her husband that I could take up to the floor and read to him and get his response and bring it back to her. And that, just asking that question, what matters to you made such a tremendous difference. It went from completely hopeless therapy session to one where we made meaningful progress and a meaningful difference in her life. And after that she was her happy, spunky self. And

I'm happy to say that she made it out of here. Another example of using the what matters to you question is an incorporating it into therapy, is I had this gentleman with a stroke and severe severe Broca aphasia. He couldn't even say his name when I first met him. So we were trying to figure out a way to help him participate more fully in life. And I said, okay, well what matters to you? And not in as many words, we had to do a lot of charades and stuff like that. But he told me, I want to be able to go out for lunch or for breakfast with my friends and I want to be able to keep up to the conversation. So our therapy was printing off all the menus of all the restaurants he went to with his friends and practiced ordering food.

So I was the waitress and we role played and I would say, good morning, sir, how are you today? What can I get you to drink? And he would verbally tell me what he wanted to drink and we did that for quite awhile. Now this was a gentleman who didn't really see the point of therapy at times. He had very poor insight in self-monitoring, but that was something that was hugely important to him, is that he could go out for coffee with the guys. So he... That's just another example of how we can use that question and the answers we get from it to shape our therapy.

Okay, so in summary, the international classification of functioning framework and evidence based practice encompass essentially the same concepts. We must move past traditional assessment and intervention towards participation and performance in a real world setting. So narrative-based practice allows us to do that. It allows us to ask the most important question in my mind and healthcare and that is what matters to you. So without further ado, I'd like to finish with a quote and this quote is, "All sorrows can reborn if you put them into a story or tell a story about them." And I really like the way that sums up narrative-based practice. Thank you very much for listening and I'd be happy to try to answer any questions or respond to any comments that you may have.

- [Amy] Absolutely, well, thank you so much. We really appreciate you sharing some very powerful, your own personal narrative as well as some very powerful ideas for therapy and we do have a good 10 minutes so that if there are questions, I certainly do invite everybody to enter those in now if you are interested and I'll kind of as we wait to see what kinds of questions do come in. You sort of answered this as you were giving examples at the end, but with the ethnographic interview questions, even though it's interviewing, at first I thought, okay, so this must be for the assessment piece, but I'm guessing it's more than just that. Correct?

- [Janelle] Yes. I personally feel that it can be used kind of as a dynamic assessment throughout any therapy session actually. It's not just to be used just in the assessment phase because our patients change and their wishes change so frequently that if we stick to what our initial assessment says, we're not paying attention to what we need to.

- [Amy] Great, that makes a lot of sense. Camilla is... Let me open this up a little bit more so I can see the question. Hi Janelle, I don't have any questions, but just wanted to say great job. This was an incredibly practical training full of immediately implementable tips and strategies. Thank you for sharing your story with us. You are a wealth of knowledge and incredibly inspiring person and therapist. I was certainly thrilled to see you were the presenter today.

- [Janelle] Aww, thank you.

- [Amy] And Caroline is also saying excellent presentation. Thank you for sharing your personal experience. Cheryl is asking, you do not mention use of standardized measures, so how do you assess deficits in conversation, vocabulary, syntax et cetera or is that not important?

- [Janelle] No, that's definitely important. I do mention at the beginning that you know, as part of the ICF we do use those standardized assessments. The more important part, well, not necessarily the more important part, but a great supplemental part to look at participation is the narrative-based assessment. So I definitely, I use the web, I use the CLQT, I definitely use other assessments for sure because otherwise, how do we know really what we're focusing on? But the narrative-based part is to find out what matters to the patient in order to focus our therapy towards treating those deficits in a meaningful manner, if that makes sense.

- [Amy] Absolutely. So do you include any caregiver training and if so, what do you like to see as a focus?

- [Janelle] It honestly depends on the patient and the patient's wishes. Whether how active I am with caregivers. I do think it's very... Caregivers obviously play a very important role. But I also know as a patient that sometimes we just want, I just wanted therapy on my own. I didn't want to have to burden my family members. So like it's a hard... It depends on the patient, I would say. If the patient's open to caregiver training, I think that's wonderful. And for the gentleman I mentioned with the stroke, his wife came and sat in with us for one session each week minimum just to carry over any of the recommendations and also help interpret I guess the patient because at times I didn't know what he was like pre-stroke and so she would tell me, you know, this is what he really enjoyed doing. And do you think this is something that we could incorporate into therapy? So, ultimately I think you have to use your clinical decision making on how much to include the caregivers based upon the patient's wishes.

- [Amy] Sure, and that makes a lot of sense. And I'm wondering too, are there ever times that you may ask a caregiver and I don't know if this crosses over into outside of our scope of practice, but that you would ever ask a caregiver what they would like?

- [Janelle] Oh, that's a tough question.

- [Amy] That is a tough question, I know.

- [Janelle] Again, if it's... It depends a lot on whether the patient has the competency and the capacity to make their own decisions as well because I have had patients that aren't able to make their own decisions. So a lot of that does fall more on the caregiver. Yeah, that's a tough one. Yeah, I don't whether I have an answer for that.

- [Amy] It's not an easy... I'm sure there is no easy answer. I was just curious if you've ever run into that situation where like you said, depending on the communication abilities or a particular patient and if you're getting a good feel from the family that they are very involved and want what's best for the family or for their loved one, would you ever reach out and say, okay, what is it that you would like?

- [Janelle] And that gets dicey too because sometimes the families schools aren't the patient's schools.

- [Amy] Absolutely.

- [Janelle] So I think as long as I... If a patient is competent and has the capacity to can make their own decisions, I would never go to the family without their permission just because I think that's stepping over boundaries and taking away their autonomy.

- [Amy] Absolutely, just curious but I'd just to ask that question. There is another question that just came in. What is the first thing you do when you meet a patient for the first time? Use your narrative assessment and ethnographic interview to collect communication skill data? How long are your sessions? It's seems narrative assessments can be time consuming as people do love to talk about themselves.

- [Janelle] Yes, you're exactly right. So the first thing I do is try to establish rapport with patients. So I just go in and introduce myself and I start asking like just the broad questions, the grand tour questions because I find if we jump in my perspective, in my experience, if I jump right into the standardized assessment, that can be a little off putting for patients. So I usually just try to get some of their personal narrative at first. I am fortunate with where I work that I don't have specific time limits for working with patients. So it's all how I can manage my caseload determines how long I have to spend with them. And some people really do like to talk. So one of the little tricks I've had is I will tell one of my colleagues, hey, if I'm not out of this room in 15 minutes, I need you to page me overhead. Because that way you're not offending the person by having to leave, but you can actually move on to the next person.

- [Amy] Interesting, okay. Very good, thank you. And then another question is how have you graciously managed talking to and treating patients who have not yet received their prognosis or diagnosis, but just went through our resection or biopsy?

- [Janelle] Oh, that's a big one. I find it so hard when I know the information and the patient isn't informed yet and it's a very very difficult situation to navigate because sometimes there's a pretty big delay between the pathology results coming back and the doctor and the healthcare team knowing what's going on and before the patient finds out. So I usually just use hypothetical scenarios and just say, you know, we don't know what's coming, we don't know what is going to happen, but if A, B and C were to happen, here are some of the things we need to maybe start looking at or start working towards. And just giving little tidbits of information because it's very overwhelming as the patient with how much you're given. So I don't like to bombard people, but I also like to give them a little bit of preparatory information because there's nothing worse than being in that limbo and not having a plan.

- [Amy] That makes a lot of sense. I think those are some really good tips for sure. Okay, so that does bring us to the end of our questions for today. So again, on behalf of speechpathology.com, Janelle, I'd just like to thank you so much for sharing your story, for sharing your knowledge with us and we really do appreciate your time. So thanks to our participants as well, we certainly do appreciate you joining us today and look forward to seeing you again soon. Take care everybody.

- [Janelle] Thank you so much.