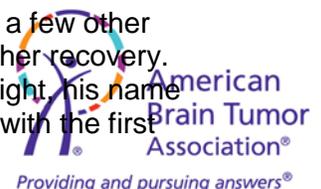


American Brain Tumor Association Webinar

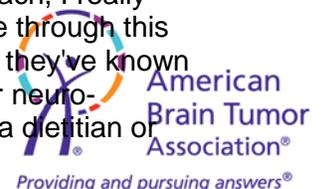
Keeping a Focus on Function

>> Welcome to the American brain tumor association's free educational webinar series. Thank you for participating in today's webinar. Today's webinar is on keeping a focus on function and will be presented by Sam MD. All lines during our webinar today are muted. If you have a question you'd like to ask, type and submit it using the question box in the control panel on the right-hand side of the screen. The doctor will answer questions at the end of his presentation. In the next few days, you'll receive an Email asking you to take a brief survey to evaluate the webinar. Please take a few moments to share your feedback which is important to us as we plan for future webinars. Everyone that completes the survey will be entered in a quarterly drawing to win a 50-dollar Target gift card. Today's webinar is being recorded .the recording will post to the website on the any time learning page shortly. Registered participants will receive the webinar recording link in a follow up Email once it's available. Let's pause for a moment so we can begin our webinar recording here. The American brain tumor association is pleased to welcome you back to our webinar series. Our webinar today will discuss keeping a focus on function. My name is Antoinette, program manager at the American brain tumor association. And I'm delighted to introduce our speaker today, Dr. Sam SHAPAR. He has dedicated his career to changing the culture of cancer care. Leading the cancer rehabilitation program at the rehabilitation institute of Chicago, RIC, he has extensive experience in assessing and treating cancer survivors of all diagnosis throughout their continuum of care. Through RIC and his association with the Robert H Lorrie comprehensive cancer center of northwest university, he helps cancer survivors thrive through functional restoration and fitness. Thank you for joining us. You may now begin your presentation.

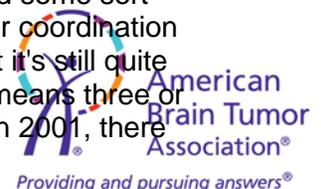
>> Thank you for the introduction, Antoinette. And I'll be moving forward. We'll go through a wide variety of topics today. We'll hopefully answer questions you have toward the end. First up, the title of the talk today is keeping a focus on function. From my aspect. Function is how I look at all patients. We'll go through this detail by detail. My first slide, just to let you know, I have no disclosures before getting this started and we'll jump into objectives. My first hope, I hope you guys take away my goal of defining the physical role of patient care. Understanding what a PHYSIOTRIST does. Hopefully we have awareness of unique functional issues for brain tumor survivors and understand the comprehensive nature of cancer rehabilitation throughout their continuum of care. A physician specialist in physical medicine rehabilitation. You may have heard the term PM and R. Or rehab doctor. Or PHYSIOTRIST. There's different names that leads to confusion. The focus is a medical specialty emphasizing the treatment of functional loss produced by medical, surgical, illness, or disease process. We really look at the function of the whole patient. And by focusing on function, we may look at different aspects. Even though a patient may come to me with a specific problem, in order for us to focus on function, we need to look at the big picture as a whole. So as some people may recognize our specialty in the field, you can see on the current slide, this was senator mark Kirk here in Illinois that had a stroke and was seeing a PHYSIOTRIST and got rehabilitation care. Some of you may recognize Christopher Reeves who had a spinal cord injury and had rehabilitation care. And a few other cases in the news. Gabby Gifford, she looks much different now. In the course of her recovery. She had a brain injury due to a gunshot wound. And this gentleman in the upper right, his name is Jesse Sullivan, he was in the news approximately a decade ago. He's the man with the first



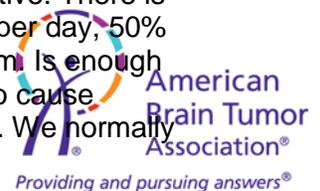
bionic amp, related to amputees. As I highlighted here. Most people don't hear about cancer patients and brain tumor patients and how they relate to it. So oftentimes we treat patients with amputations and injury to the spinal cord and injury to the brain, stroke, musculoskeletal injuries, arthritis or sports related injuries. Pain, cardiac disorders, neurologic syndromes. But many patients with benign and malignant brain tumors can benefit from our care and expertise. And we'll move in to where to start. What does this mean for patients who are undergoing this process? So my where to start slide. So according to the national cancer institute, and national coalition for cancer survivorship, a cancer survivor starts from the time of diagnosis through the balance of his or her life. As we've become better at treating cancer with more focused surgery and radiation and different clinical trials and immunotherapy our balance of life is increasing. We're better at treating the cancer. But we're not necessarily set up clearly as patients move along this course of spectrum of treatment and recovery and trying to get back to life of who really manages and helps the patients and their families guide through this process. So when we look at issues that patients may face, their short-term effects such as if you take a medicine, it may make you ill or nauseous and give you side effects that are generally short-term while you're taking it or soon after taking the medicine. Long-term effects are persistent. They often begin during treatment whether this is radiation or chemotherapy or surgery and continue. A classic example used in our cancer survivor population is neuropathy. Some people take chemotherapy and they get neuropathy during treatment and it hangs along. Late effects often come along long after treatment. The part that we see commonly for late effects may be radiation. So during radiation, we may have side effects. We may have some long-term effects but sometimes moving down the line a year or two or even later, we may see effects from prior radiation due to the nature of how the radiation works and continues to damage the body. These late effects, we're learning more and more about. As we mentioned, the balance of life is increasing, as people survive and live longer, we're noticing things that may have happened prior to their treatment. And things we need to recognize on to try to prevent, and try to help if they suffer these side effects. When we focus on rehabilitation, we need to look at different aspects of survivorship and the experiences. Everyone is unique. So two people may have the same type of cancer, may have the same type of treatment, and may go through the same protocol. May even be the same age. But we're all different. And we need to kind of take that context into account. As we move through, we want to look through the disease itself, what type of cancer or tumor, where is it effecting? What part of the brain for brain tumor patients? Treatment-specific, what type of surgery, what type of chemotherapy. Hormonal. Now there's more immunotherapy and radiation. But there's also the individual specifics. Even before the diagnosis. Before they came into the system as a cancer survivor. How was their medical status or their functional status? Were there stresses from a psychological or social standpoint that we need to pay attention to. That includes are they a care giver for another family member? Are they an active full time worker? Are they a police officer? Are they a grandmother who's taking care of their grandchild? All of those pieces are important to us as we identify a plan for function to see what tear baseline was and where we can manage and treat the issues that we face related to the disease and the treatment moving forward. So when we talk about rehabilitation or cancer, brain tumor rehabilitation, how I like to think about it is it's any evaluation assisting in the function and ability in any patient with cancer or brain tumor at any point along the disease continuum. Often I'm asked at what point should we involve rehabilitation? At what point is rehabilitation a good idea? Or therapies. If we look at this definition, my approach is I don't think there's a wrong answer to that. If we're asking the question, then most likely rehabilitation care can be helpful in this process. So when we talk about rehabilitation and the approach, I really like to highlight it's an integrated team approach. And most people who have gone through this system dealing with themselves or a family member or someone they care about, they've known about this team approach. In the oncology team, they're often seeing a medical or neuro-oncologist, a surgeon, a radiation oncologist, maybe people on the team such as a dietitian or



social worker. We want to integrate with that team as well as everyone else that you see around here. From a rehabilitation physician, or physical therapist, psychology, sometimes we involve pharmacists. We have occupational therapists and dietitians. And really the idea is, the focus is on the patient, their family, their support system to how we're trying to focus it on. And getting rehabilitation at the best is when everyone is working together. When we want to get a scope of the broad spectrum of what type of unique issues we face and why is it important that we pay attention to these as we increase survivorship. I think it's nice to halftime these numbers that come out -- to highlight these numbers that come out every year or so. The American cancer society comes up with numbers based off their collection of data. They're usually a year or two behind based off collecting the data. January 1st 2016, there are over 15.4 million survivors of cancer in the United States. And it's expected in about a decade, and now less than a decade, January 1st 2026, they're expecting over 20.2 million survivors in the U.S. So obviously these numbers are increasing. When we speak of brain tumor patients, currently there's almost 700,000 brain tumor survivors in the U.S. That includes primary, malignant, and nonmalignant brain tumor, and CNS tumors. It was estimated that over 77,000 new cases of these came about in the U.S. And you can see on the bottom the break down. So obviously compared to some other cancers, the numbers may not be as high with brain tumor patients, but still looking at these numbers, they're still quite significant. It makes this from a medical perspective, from my and perspective, understanding that we need to focus on this population that's growing and growing and something that will affect all of us. Some of the most -- some other details that we pay attention to regarding brain tumors. It's the most common cancer for children and teenagers from ages 0 to 19. Meta static are the most common time. Most commonly from lung and breast cancer as the primary cancer. The most common of all malignant brain and central nervous system tumors is glioma tow ma. And meningeal is over 50%. Incidence is small. If you can compare it to the number of patients with lung, breast, or colon cancer, it can be a source of significant functional impairment due to where it effects. The brain controls a lot of our function. If we have damage to the brain, it has significant effects. A higher percentage of patients may have functional impairments verses other patient populations. The exciting part is there's potential for many of these patients no not only require but benefit from rehabilitation services. And we'll go through some of these details of how we've identified this moving through the history in terms of research and where we are currently. So going back to 1978. Dr. Lee man and her colleagues in Seattle screened 805 patients. By screening I mean looking at a chart and assessing them. They identified rehabilitation goals. And they reviewed the hospital chart and performed an interview and physical exam. What they did within these patients is identified and developed optimal rehabilitation programs based off what they found. And compared that to what they got. And I apologize to anyone for the slide, unfortunately, because it's an older journal, it did not come out as clean. I had to photocopy this picture. If we look through the different types of cancers, these are the numbers of patients they saw. The nervous system would include the brain. Sorry to highlight this. If we look at the percentage of people here over 80% of patients with nervous system tumor, including brain tumors had some sort of physical medical problems. If you look at the graphs compared to every other cancer, it was the highest percentage of problems compared to any other disease or cancer type. So some people would say, 1978, that was a long time ago. We've become much better at healing patients and not causing as much damage. But if we look forward, moving forward to 2001, there was another study that looked at 51 adult patients with brain tumor diagnoses. We can see with a mix of glioblastoma, meningioma. And metastatic brain tumors. The most common deficits. Impaired cognition, which means thinking, 80% of patients had impaired cognition. 78% had some sort sophomore weakness. Over 50% had a visual perceptual deficit that goes with our coordination or how we're seeing things. If we look at the bottom, what I highlight, showing that it's still quite a problem, is almost 75% had three or more concurrent neurologic deficits. That means three or more of these plus some other ones. Clearly despite us getting better at treating in 2001, there



were still significant functional impairments we're seeing in this patient population. Moving forward again to 2012, there was another study that evaluating fatigue in 25 brain tumor patients after surgery that came into a rehabilitation unit. After they had surgery they left the hospital and went to a rehabilitation facility to continue care. And what they found is 84% of patients reported fatigue over the previous week. Again, a large percentage of these patients are effected by fatigue. Which is a common impairment that we see in all cancer types. But can significantly impair all aspects of function. And the other part I think that's helpful to highlight is insomnia was an independent significant predictor of fatigue. Commonly whether it's pain or because of steroids or other treatment aspects, sometimes the difficulties with sleeping led to some of that. But those are impairments that are important for us to manage and treat as well. Moving forward, in 2013, this was from the journal of neural oncology. There was a recognition in the cancer and the medical and neuro-oncology community, they looked at patients with brain tumors in Italy. And they evaluated for thinking. That's the cognitive impairment. For them, these are out patients. People not sick enough to be in the hospital but getting care at home. There was over 50% demonstrated some sort of thinking impairment. As we talked about multiple types of impairments, over 45% had multi-domain impairments. As you can see, this next part of the slide, types of domains we speak of when we think of cognition is language, attention, memory, how fast we're thinking, which is processing speed. They did notice older patients had higher cognitive deficits. And those who received chemotherapy as well as those who -- the tumor effected the left side of their brain. Some of those make sense in terms of how we understand brain function. But I think it's still helpful for us to associate as we learn more about what types of patients may be at higher risk for some of these deficits so we can pay attention to them earlier and sooner and intervene. Other types of functional issues that we pay attention are not unique to brain tumor patients but they're seen in many patients that we know we can help treat with various services. That includes pain, weakness, and mobility loss means difficulty moving around. ADL speaks of activities of daily living, bathing, dressing, doing our normal hygiene. Cognition we spoke about. Communication. Sometimes rolls into that. But sometimes it just has to do with speech. Swallowing difficulties, the ability to tolerate nutrition and hydration. Bowel, bladder, and sexual dysfunction which is sometimes missed when we're busy with the medical care. But it's often an important part of people's lives and relationships. Looking at the skin, whether it's related to the scalp or other issues as a side effect of treatment. Looking at the psychosocial model. We pay attention to social supports. Not only depression but anxiety and other mood related issues that can come and go during the treatment course. As well as vocation mall and vocational and economic concerns. As we mention, the other surrounding Environmental pieces about stresses from job or finances that can affect the plan we need to put in place. What I highlight in this next part is something called de conditioning. It's something I speak about to all the medical students I interact with. The residents or doctors in training, other physicians. Every time I speak of cancer rehabilitation. Some people may have heard of the term deconditioning and think I'm in bed, I get sick, I'm not moving around. And I'm out of shape. But it effects a lot more than that. I can spend hours speaking about this. But I think highlighting some important factors about where we're going to move to next is important. Because this is deconditioning has these effects in absence of disease. So this is just if we went on bedrest. Whether I had a brain tumor or I'm undergoing chemo or radiation. This is in absence of that. If I was on bedrest, there's been studies that show we can lose 5 to 10% of muscle mass per week. Complete immobility. You can lose 1% to 3% strength per day. After being in the bed for three weeks, which some patients may be due to surgery or being will, the resting heart rate can increase by 10 to 12 beats per minute. Just from being inactive. There is some evidence to show that just doing some activity. They talk about contraction per day, 50% of maximal strength. Getting up and using your muscles and really squeezing them. Is enough to prevent muscle decrease and the body from declining? Deconditioning can also cause sensory deprivation. Depression and social isolation and decrease pain tolerance. We normally



don't think about how it can decrease pain tolerance but sometimes not moving, our body gets hyper sensitive to certain issues, and other things may flare up. And that's in absence of disease or cancer or cancer treatment. Another part is cancer related fatigue. Many patients who go through cancer treatment related to brain tumors can have fatigue. Cancer related fatigue is a little different than regular fatigue. The key component is it's not relieved by rest. Some days we don't sleep well. , we're tired. We get a good night sleep. And we feel better. It doesn't dismiss that fatigue but it's different than cancer related fatigue. The different ways it may present. If you look at the slide, you can see how it may present outside of just being tired. The examples I give in terms of how to pay attention is if anyone has interacted with children or young children, sometimes when they're tired and we say they need a nap, you may see a lot of these issues. Such as no concentration or attention. They may be irritable. They may not remember things. People may actually be -- may have insomnia related to fatigue. They may be physically tired but they can't fall asleep. You may have decreased motivation. It's not just tiredness. They may present in different ways. Things that can effect this aspect of cancer relate fatigue. I break this slide up really in two aspects. We can look at this side here on the left separate from this side here on the right. The side on the left, or what I usually tell people are things I can't control. Generally, people that come to see me for rehabilitation, they have a brain tumor. Or they have a cancer. There's sometimes effects on the tumor that I can't control. They have that diagnosis. They're often getting chemotherapy. Sometimes there's direct effects of the chemotherapy that cause them to have effects related to fatigue or indirect effects. It can cause problems with your heart, your hormones, your thyroid, it can make you feel depressed. That's what I can't change. It's part of the treatment of the tumor. Related to hormonal therapy, or radiation. Seizure MEDS may cause issue or fatigue related to that. From anemia and this list down, this is things I can control. In terms of anemia, low blood count. Sometimes but supplement people with vitamins or iron. We can look at hygiene or medications to effect sleep. Some people have sleep apnea. We get a sleep test and they may benefit from a C pap machine to help people sleep. Poor nutrition, I should have this as hydration as well. Work on things to build up appetite and make sure they have the calories. Depression includes other mood aspects including anxiety that's sometimes with therapy or seeing a counselor or medications we can help that. And immobility and pain are a little more directly. People view as rehabilitation of getting people up and moving. Immobility relates to deconditioning and can cause pain. All those things can make us tired. Any time we're looking at that, I'll look again at the things I can't control verses the things I can control. We set up a program. So how do we help? That's really the next step. I've identified a bunch of issues that we may see. And impairments. But how do we know what rehabilitation does, is it helpful for the patients or their families? Luckily through my training at my current location. And my experience here, a lot of my partners and colleagues have done some of this research at my current institute where we evaluate the benefits of rehabilitation in patients with brain tumors. My partner did a review of 159 cancer patients over the course of rehabilitation here at our institute. And 72%. 72 of those 159. Nearing about 50%. Were brain tumor patients. And what she found was patients with cancer of all types, even those with cancer that spread or metastatic disease made six significant improvement in functional status during their course. Why this study was important, even now we fight the battle of insurance companies or even other doctors questioning whether cancer patients or brain tumor patients should come and benefit from rehabilitation services given that cancer is a serious diagnosis and they may be getting treatment and will rehabilitation is worthwhile. This study shows that cancer of all types, no matter how spread it was, tended to make functional improvement and her study actually showed that patients who were receiving radiation tended to do better than those who were not receiving radiation or actually got radiation before rehabilitation. I don't have a great explanation for that. But it did show patients going through treatment did well. There was another study done at MD Anderson that demonstrated similar efficiency between low grade and high grade astrocytoma. It means the

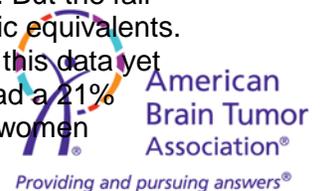


progress or the speed at which people recovered and improved in rehabilitation. Our FIM is a scale we use to judge how much help someone needs. Talking about low grade and high grade, those are patients with a lower grade tumor such as a meningioma or a higher grade astrocytoma. Both populations tended to do well in this process. We've had multiple other studies that show patients with brain tumors made gains comparable to patients who have had strokes and TBI means traumatic brain injuries. We know patients with strokes and traumatic brain injuries come to rehabilitation all the time. That's accepted. We needed to prove that patients with brain tumors can make similar gains when their brain is effected although in a different way with rehabilitation. Another study from colleagues in 2001 and 2005 shows that the cause of the brain injury is not a significant factor in how well they do. Whether it's a stroke or a tumor or surgery or a gunshot, patients -- the cause didn't make that difference. And all patients would benefit.

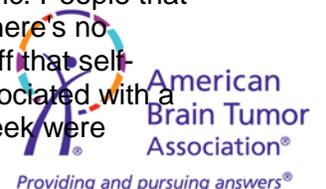
>>> Moving on to outpatient rehabilitation where a lot of patients often are. They're not often in the hospital. They may have the hospital as part of their course. We have a lot more limited studies. There was a small study. As you can see, only 10 patients that they looked at. They had a one month and three month follow up after they left the inpatient. And these patients showed functional improvement up to these three months. So they were in the rehab hospital. They went home. They continued to get better. There was a study that looked at an outpatient traumatic brain injury rehabilitation program. So these are patients who, whether it was a car accident or another injury, they had a traumatic injury to their brain. And they applied that program to patients with a primary brain tumor. They put 13 patients through and they found improvement in their function, and their work productivity, and they maintained their gains from an average of eight months post discharge. More evidence that shows patients who have this type of injury would benefit. And another type of therapy where you go to a facility, but a home neurorehabilitation. Improving effects of damage to the brain or the spinal cord. They had an improvement of function in 1/3 of patients. This is a program at home. They didn't go to a facility. 1/3 still benefited. When we look at types of therapy for cognitive dysfunction. That's the thinking function that we talked about. There's a lot of inconclusive evidence for various interventions. Some of the challenges is, as we mentioned the types of problems with thinking. Sometimes it's due to the tumor. Sometimes it's due to medication. Sometimes it's due to other aspects. And there's variable causes and variable severity. It's difficult to manage and do a study when there's such variability. Things that we do use clinically though, include medications that includes MODAPHYNIL. There's new vigil, some physicians do use that. MethylPHINODATE also known as Ritalin. DENOPOSOL is something patients may have heard of related to dementia. And dopamine agonists. Increasing the dopamine supply in the brain. We generally call these medications neuro-stimulation. That means we're trying to stimulate the brain to help recover. And outside of medications, we have our speech-language pathologists who don't just focus on speech, but they focus on cognitive therapy. That's in essence exercise for the brain. And sometimes that's the main focus that we do for anyone who has cognitive dysfunction to help us assess the plan. When we talk about exercise, this is my favorite part of the talk. And the most -- the thing I highlight most to all the patients I interact with is exercise interventions. No one argues or has concerns about the benefits of exercise for our cardiovascular health, which is our heart and our blood vessels, our pulmonary or lung health. Endocrine, patients with diabetes or other hormonal problems. People with stroke or Parkinson's they often get exercise, our well-being and psyche as we exercise we tend to feel better. As well as quality of life. What does this mean for the brain tumor population? The American cancer society doesn't differentiate between different types of cancer diagnoses. They do recommend in order to see a protective effect in terms of the benefits they recommend at least 150 minutes of moderate intensity weekly exercise or 75% of vigorous exercise activity weekly. When we look at this, this



is often a challenge and intimidating to people who look at these numbers and they say there's no way I can get that. I self-admit, I struggle to meet these activity numbers. But what I want to highlight is the goal is to reach those numbers. But just because we don't reach those numbers does not mean we don't get a benefit from those numbers. I'll talk more about that in the upcoming slides. So another way to highlight the benefits of exercise, if we look here in the upper left, here's a normal cell. Over here, in the bottom right, there's a neoplastic cell. A cancer cell. There's multiple steps it takes for bodies to have difficulties for this normal cell to become neoplastic. Within these steps, cancer can develop and exercise has been shown to prevent some of these changes from happening from normal to neoplastic. And that's in essence what this next slide describes. It's been shown to alter the specific pathways of tumor initiation. And carcinogenesis. We may hear about that. Core -- so again you don't have to pay attention to the details. I wanted to present it to you. So you at least see the information. This is the important idea of why I emphasize exercise. When we talk about exercise and how it can help us outside of that important detail when we're looking at the microscopic level. When we look at cancer related fatigue, there were studies of 32 cancer patients with mild to severe fatigue during and after chemotherapy and they did three weeks of aerobic and resistance training program or an exercise program. And after three weeks, they had a 25% reduction in their global fatigue. Which is pretty good. So if we talk about most medications that come to the FDA and get approved, if they have 25%, they're going to be scoping through and most people are going to be buying that right up. But this is just exercise. No medications orphan centric, just getting people up and moving. Other things we do to treat this outside of exercise, I mentioned these medications, some of these medications for neuro-stimulation as well as steroids and antidepressants. We use cognitive behavioral therapy. We don't think of this as a thinking problem. Sometimes it can affect our thinking. Changing our brain processes. Looking at sleep hygiene again and energy conservatizing techniques -- energy conserving techniques. Start as simple as teaching people body mechanics. How to move out of bed, how to dress without struggling, sometimes we talk about equipment or adaptive aids to help them. A simple example is oftentimes people may have difficulty to get socks and shoes on. There's some tools. One is a sock aid or a shoe horn. Oftentimes people get the small shoe horns and they have to lean down any way. It can be as simple as getting a long handled shoe horn. That allows people not to struggle and it saves energy to do other activities. And again, to add on to exercise, we often talk from a medical standpoint of cardio pulmonary fitness. That in essence means our general fitness level. Some of you may have seen some the commercials where people, for instance a sports drink brand where they're wearing a mask on a treadmill and they're measuring, they have all these monitors, what they're really in essence highlighting in that commercial is measuring this peek oxygen consumption, the mask is measuring how they're breathing and using oxygen. This fitness level of how well we use oxygen is a key predictor for mow in MOTALITY. There's been a lot of research in our cardiac population. And our cardiologists who are assessing the heart often that if you have a 12% improvement in survival for men and a reduction in death by 70% in women for every one met increase in aerobic. One metabolic equivalent equals this fancy formula. Our body is always expending energy. Just sitting here. If we're sitting at our desks right now or a table listening to this, we're extending about one metabolic equivalent. Our body takes a baseline amount of energy. If we're walking at a fairly brisk pace, not slow enough where we could read a magazine. And not fast enough where we're jogging and huffing and puffing but a slow pace, that's a three metabolic equivalent activity. You can often just search on the Internet and look up these metabolic equivalents with different activities and you can find how they're rated. Obviously they're a little generalized. But the fair bet is usually about 1 metabolic equivalent when sitting. A brisk walk is 3 metabolic equivalents. In the breast cancer population, it's been shown, and unfortunately we don't have this data yet in our brain tumor population. Patients who are survivors of breast cancer, they had a 21% lower cardio pulmonary fitness than age matched healthy sedentary women. Not women



running marathons every week. Just people of their age group who are sedentary. Not very active. Just the fact that they had treatment of cancer, we do know it can affect our heart and our fitness level. So when we talk about exercise and function, I think these next few studies are important for us to pay attention and bring home some of my final points and hopefully we can move forward to the questions soon after. This study here looked at a total of 544 patients over ten years. You can see that time frame. 96 to 2006. And they looked at patients with a KPS. A performance scale of 80 or greater. I'm going to jump to this next slide so you can see this scale before we go forward. The scale is a 0 to 100 scale. 100 is someone who is normal function. There's normal. No complaints. 0 is people who have passed away. So generally, in this study, they looked at patients who were 80 or above. 80, the low end is normal activity with some effort and some signs or symptoms of their disease. This is not specific to brain tumors. It's used for all types of cancer patients. They looked at patients who were pretty well functioning. Around half of them had a subtotal resection. Not all the tumor was taken out. Subtotal is part of it. And total would be almost all or all they could see. They found the mean survival time of these patients were 11.6 months. Within this population over 50%, or 56% lost functional independence. And that's a KPS score less than 60. So if we go back to this slide, so over half the patients at some point continued to lose function and that was requiring occasional assistance but able to care for most of his or I should say her personal needs. So at some point in history they started here and they came down to here. Over 50% of them. And the median functional independence length is ten months. That means they were doing okay for a majority of their care. But maybe towards the end. Given that the survival time was 11.6. At ten months they started having challenges. People who tended to have the prolonged survival or function, so if you had improved preoperative and immediate post-operative function. If your function was good before surgery and right after surgery, which is considered within one month, it was associated with prolonged survival. The greatest survival in patients with KPS greater than 90. That's near the top of the scale. And they found that the post OP function was a stronger correlation than pre-op status. How they came after surgery within that month was more predictive than how people were before surgery. Why I highlight that part is if we pay attention to function. There is this relationship with people doing better because they're functioning better. And the next study as we move through here, we'll talk more about that. But there are some other correlations with function. There's been studies that show that people who have that high functional level tend to do well with prognosis. Patients with a primary glioma to ma. The glioma to ma that didn't develop from a lower grade tumor. Glioblastoma. People who are older at the time of surgery, not too surprising. People with heart disease. Or people with a new post-operative motor deficit. That means after surgery they developed new weakness. These are just correlation factors. Because someone has one or the other of an older age or heart disease does not mean they won't do well and just because someone has in essence a treatment with this doesn't mean they'll always do well. But for us, when we understand what patients go through, this may help us through this process. This last study, somewhat my take home point over all, we look at the efficacy of exercise. The study was done in 2011, and they looked at 243 adult patients with grade three or four malignant glioma. The higher grade tumors. They started off with this KPS of 70. That's a decently high functioning person. They administered a questionnaire to assess people's exercise behavior as well as doing a test of a six-minute walk test. Which basically monitors how far they walk in six minutes. And they followed these patients up for over two years. This first slide shows the six minute walk test and the survival time you see of how people survived and these are in meters. You don't have to pay attention to how the cut offs are. As you can see, most of these lines are symmetric. People that walked under 390-meters or people that walked almost 500-meters on this test, there's no difference in survival they found over this course. What was important, is based off that self-assessment of exercise, is people that exercise over nine hours a week were associated with a median survival of 21.84 months. People that exercises less than nine hours a week were



associated with a median survival of 13.03 months. That is a pretty significant difference. Just to highlight, it's not a cause and effect. It is a correlation. Because they didn't do exercise as an intervention. But it did show us that patient's ability or exercise behavior. Not necessarily their capacity of function was important in terms of survival. So moving forward through the spectrum is, I want to look at my patients, I want to improve their function, and improve their fatigue, and improve their symptoms that are limiting their exercise so I can allow them to exercise. So hopefully we can think about this effect improving survival, improving their ability to manage treatment. To improve that part. So it's not just quality of life and doing what you need to do. Which is important, but hopefully, as we get more data, we may see more benefits of exercise actually changing survival. And I know I mistakenly did not clarify the met hours. As I talked about before. Three mets is a brisk walk. If we talk about met hours it's hours that we do the met activity. So a brisk walk, which is three mets, for three hours is nine mets. So three times three is nine. So we can look at the different activities and that's usually where we start to get people to move up and up and try to get that brisk walk and just get people moving to build up so we can build this activity in. The challenge that we often face is not just those symptoms but often people's perceptions of their ability. There was a study that showed they interviewed 106 brain tumor survivors and had them completion a questionnaire. 75% had grade three or four disease, 47% of patients or survivors perceived themselves as able to exercise during treatment. That's under half of the patients thought they could exercise during treatment. And only 44% wanted information about exercise during treatment. The numbers did increase after words. But if we highlight what I've just mentioned in the last few slides and talk about rehabilitation and talk about exercise, from my end, if possible, I'd like to get involved early and often to build people up and not just wait until we're done to get started. So the next step is engaging patients family, friend, medical personnel to take further interest and active roles in rehabilitation and exercise, determine consistent measures to track these outcomes and issues, so how we can determine how patients are having symptoms, how we can intervene. And change that culture. So we change moving through here, these under 50% of people thinking they can be involved or even interested in being involved to over 50%. And then hopefully 75%. And then hopefully everyone is getting part of their care. And it's just as important as their care as any other part. I'm biased as a rehabilitation doctor, but that's my perspective. And I think this is the end slide of a disclaimer. And I think we should be ready for questions, Antoinette.

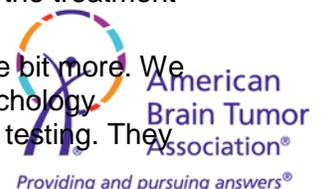
>> Yes. Thank you, doctor. That was a great presentation. We'll go ahead and move into our question and answer segment. And if you have a question you would like to ask, please type and submit it using the question box in the webinar control panel on the right-hand side of your screen. So let's see.

>> Do you know of any NCI designated cancer centers are required to have PHYSIOTRISTS on staff?

>> Currently, in terms of the requirement with the American college of surgeons actually certifies many cancer centers. Several years ago they came out and required cancer centers to require rehabilitation care. They did not identify specifically a PHYSIOTRIST. It could be a therapist, it could be a variety of professionals that they identified as rehabilitation. It does vary quite a bit. A lot of the centers do have PHYSIOTRISTS involved at least peripherally. The challenge is sometimes the oncologists aren't aware of the benefits we can offer. There's no requirement for a PHYSIOTRIST. At a certified cancer center there's a requirement for rehabilitation services. That's still developing.

>> Thank you. I have another question. Where would a neuropsychologist fit in in the treatment team in?

>> The neuropsychologist, if I sometimes have more time we delve into that a little bit more. We sometimes use them. When a neuropsychologist helps, they're trained with a psychology background with a fellowship in neuropsychology and they do extensive cognitive testing. They



interview the patient. Get to know them. Their education, and those domains of thinking, language, processing, attention, memory. They do specific tests and these tests can sometimes, you know, the total of neuro-psych testing can last maybe even four hours. To really break down and tease where those deficits in thinking are. So sometimes if we have a difficult time assessing that, or we want more details regarding someone going back to work or making certain decisions or really just having a challenge, we sometimes do the neuro-psych testing to give us that extra detail. Our speech therapists sometimes do bits and pieces without doing the whole neuropsychology. But we definitely utilize them frequently. The challenge that sometimes we face is as an outpatient, sometimes insurance coverage of that can be limited.

>> Thank you so much for that answer. And we do have a question what is the difference between home verses outpatient rehab programs?

>> So when we speak of the settings of rehab programs, generally when we talk about home programs, that means someone comes to the person's physical home. They don't leave the home to exercise, a therapist comes in the home and works within the home environment. Outpatient is considered going to a facility. If you go to a gym or a hospital where they have equipment there. And you're meeting the therapist like an appointment. That's the distinction there. Oftentimes with home health services, people who have difficulties getting in and out of the house. We may start with home therapies before we transition to outpatient therapy when it's easier for them to get back and forth.

>> In your experience, which brain tumor related impairments respond well to rehabilitation and which respond poorly?

>> Globally speaking, I've seen benefits in all impairments with rehabilitation. I've been seeing patients with brain tumors for an extensive period of time with a wide variety of where it is. The one part that's most challenging is people with the cerebral dysfunction. The part of the brain in the back of the brain that effects coordination and balance and can cause dizziness and some of the visual stuff that goes along with that because of the coordination. That's not just related to brain tie mores. People with strokes or injury to cerebellum otherwise, that's a challenge to have rehabilitation interventions. Do we get some people better with rehabilitation, absolutely with cerebellar problems? But talking about weakness or thinking problems the cerebellar difficulties are the most challenging.

>> Thank you. Do you have suggestions for insomnia?

>> That is somewhat of a loaded question because there's so many different factors that can effect insomnia. Starting off with what I mentioned. The things I can and can't change. Sometimes it's related to just the pedestrian occasions and the treatment. One common piece we use and I just had the patient the other day, patients sometimes are on steroids. And sometimes they're twice a day or multiple times a day. We sometimes move the steroid to make sure it's not given too late at night. If people take it at 8:00, it can be stimulating. If we take it closer to dinner time they may sleep better. Other times we talk about sleep hygiene and how they're sleeping in general. A common question if anyone has insomnia, I ask, do they snore, nap, and feel rested in the morning. Sometimes they talk about difficulty sleeping before treatment. For though patients we often talk to their primary care doctor and maybe do a sleep study and hopefully treat them. Maybe they have a primary sleep problem unrelated to the treatment. And then sleep hygiene. Basic things to talk about. Most people might have heard this in the news or otherwise, no TVs, no reading in bed. Get off the phone when you're in bed. We don't want things while we're in bed to stimulate us. When we go to bed, bed is our place to sleep. If we do other things in bed our body gets used to doing other things in bed. When we go in there we're still stimulated. The last part, if we can't control external factors, there are medications we can use. There are things non-medication wise that we can assess for before we add medication to someone's regimen.



>>> To what extent do diet and nutrition have an impact on rehabilitation efforts?

>> So I will preface that I am not an expert in diets or nutrition. I'm not a dietitian. My expertise comes from my medical background. We have some interest. But for specific questions about diet and nutrition, I defer to our experts from that end. What I can say is we need calories and water and hydration to function. If we don't have enough calories or hydration our body will fatigue and not function. When I'm in Chicago, and even though our winters are cold, our summers can be hot. If someone is out in the heat, they can have difficulties with just being hot and sweaty. And I say sometimes we get hydrated and we feel better. Some simple activities of staying hydrated throughout the day, drinking water is appropriate and medically appropriate and there's no restrictions and making sure you get steady calories throughout the day to make sure our motor continues to run as we're dealing with not only the cancer and cancer treatments as well as our recovery and exercise that we want to do. So I talk to all my patients about that. If we need further details, I may refer them specifically to a nutritionist or a dietitian. But we start with the basics. If they're not drinking much throughout the day, we start with that. If they're not eating enough. We start with that.

>> Thank you. And we do actually have a webinar coming up next month on diet and nutrition for brain tumor patients. With a registered dietitian giving that. I'll talk more about that later at the end.

>> Go ahead.

>> I was saying that's a perfect transition.

>> Definitely. I do have time for one last question. Does the insurance cover rehabilitation programs?

>> So rehabilitation is part of -- everyone's insurance program if they have some basic standard including Medicaid and Medicare. The rehabilitation benefits vary significantly. And sometimes it's split up in ways that don't necessarily make common sense. Most rehabilitation facilities should have people to help you work through that process. Regarding how much benefit you have in terms of how many sessions or how much money within your insurance needs to go through. So if you have interest, or you're seeing a PHYSIOTRIST. Being your own advocate and talking to your insurance company. But all the patients I see, we work through insurance primarily.

>> Great. Thank you so much. That is all the time we have for today. And again, we want to thank everyone else for joining us, and Dr. SHAPARA for his wonderful presentation. ABTA has a variety of programs available to help connect patients and care givers with information and resources to help support them in their brain tumor journey. As well as publications and resources for health care professionals. For more information, visit ABTA's website at WWW.ABTA.org or call the ABTA Caroline staffed by caring professionals (800)886-2282. Let's pause for a moment to conclude our webinar recording. We invite you all to continue to check back at WWW.ABTA.org for the any time learning page, a library of free on demand webinars featuring rebound experts addressing a wide range of brain tumor topics from treatment options and tumor types to quality of life and system management. As I mentioned earlier our next webinar will be on diet and nutrition for brain tumor patients on Thursday March 30th from 1:00 to 2:00 p.m. central time. Brain tumors and their associated treatments have the potential for a number of side effect, fatigue, nausea, vomiting, taste changes, difficulty swallowing. Engaging in healthy diet and nutrition habits play an integral role with traditional cancer therapies and for the management of symptoms resulting from these treatments. Join us for an interactive webinar that focuses on strategies for optimal nutrition, before, during, and after cancer treatment. Hear from Hannah, registered dietitian from Dana FARBER cancer institute who will discuss foods that will help alleviate symptoms and side effects and those that can support



optimal health including certain diet and supplements. To register visit WWW.ABTA.org. Click on brain tumor information and then upcoming webinars. This concludes our webinar. Thank you for joining us. And please be sure to complete the evaluation survey you will receive by Email tomorrow. A reminder that everyone that completes a survey will be entered in a drawing for a 50-dollar gift card. This concludes our webinar. And you may not disconnect. [Event Concluded]. And you may now disconnect. [Event Concluded].

