

**SPEAKER:** So our speaker today is Dr. Thomas Bergquist, who's an assistant professor in psychology at Mayo Medical School, and he's also the program director of the Mayo Brain Injury Outpatient Program. Dr. Bergquist received his doctoral degree in clinical and medical psychology at the University of Alabama. He did his internship in clinical psychology at Oklahoma University Health Sciences Center and then did a two year fellowship in clinical neuropsychology at Mayo. He's given numerous regional, national, and international presentations in the areas of brain injury, and rehabilitation, and disability, and has authored or coauthored over 20 scientific publications and several book chapters.

He was awarded the Lifetime Achievement Award by the Brain Injury Interdisciplinary Special Interest Group of the American Congress of Rehabilitation Medicine, and he's also co-investigator of the NIDDR-funded male TBI Model System Center. His main research interests include rehabilitation following acquired brain injury and coping with disability. And you see the title of his talk for this afternoon. Dr. Bergquist.

**THOMAS BERGQUIST:** OK, can everyone hear me? Wonderful. I am honored, humbled, and probably a little anxious to be here today to talk to you about what I do every day. And I'll go over some clinical and some research data about that and what it is.

I think I'll be talking specifically about persons with acquired brain injury, given that's what I do and that's what the program I work in does. Most of my clinical day and research time is spent in the division of brain rehab and PM&R. But I think, I hope that what we'll be talking about will speak to other patient populations as well and provide a model to conceptualize individuals, particularly those with chronic health problems which I think is a whole lot of what all of us do clinically and research-wise every day.

But of course, to start we have to go with the disclosures. And basically the slide says that neither the committee nor myself has anything to disclose. And we always, of course, want learning objectives. I won't read these out, you can look at them here quickly. And I hope that over the course of the next 50, 60 minutes we'll be able to meet these and maybe even some more.

But first just to start with to kind of lay the groundwork, a definition of terms. There are several terms we use through here. One of them is acquired brain injury. And that's just simply an umbrella term for anyone that's acquired a brain injury due to some medical condition, brain trauma, brain tumor, craniotomy, stroke, infectious process, a whole variety of other causes that's caused brain dysfunction to result in a whole variety of difficulties thereafter.

Within that umbrella, one of the more common causes, and the one that's actually been probably the most researched, especially from a research standpoint and a treatment standpoint, rehabilitation standpoint, is traumatic brain injury. And I would imagine you've all at least heard of that. It's just someone that has brain trauma, anywhere from a concussion-- there's a lot of press about especially sports concussion-- one of our new emphases in the new sports medicine center that's opening will be sports concussion opening just the next few weeks-- all the way to people that have very severe traumatic brain injuries who might have prolonged the course of coma and lifelong difficulties.

And then chronic brain injury is a term that's relatively new to our whole discussion. And that gets the whole idea of chronic health problems. That individuals, yes, they have a traumatic brain injury, there's a lot of acute care that's done with them, a lot of acute rehabilitation, but many of them, a subset of them, go on to have chronic lifelong problems. And so in the rehab field there's been a push-- a lot of it's from consumers and their families, people who have survived brain injury, to really have this chronic model of health care that we use is similar to what used in other populations that have chronic health problems as well.

And that's kind of a new discussion, but it's one which fits into the discussion today as to then how do we help these individuals who've had this acute injury? They went through some medical interventions that have been fairly intense, but then they go on to have chronic health problems. And I think a lot of what we talk about today will speak to that.

Just to talk about the scope of the problem-- and again, I'm going to focus mainly on traumatic brain injury, but with the understanding that in our rehab program we take people with any variety of acquired brain injury only of which is subset is traumatic brain injury. But the slide here from CDC, and it's over 10 years old, I think the data is probably similar, it's just to show you this is a common problem. I mean, there's a whole lot of people that have traumatic brain injury every year, a significant minority of which go on to have longer term problems, sometimes lifelong problems. So in comparison to other common health problems, this one's fairly common.

This is another slide-- I believe this is from CDC as well, I apologize I don't have the reference-- that shows of those that have a brain injury, how many go on to be hospitalized, how many actually die from that injury, and how many have long term, often life-long disability. And that gets into that term chronic brain injury. It isn't people that are chronically having brain injuries necessarily, but they've had a brain injury and they have chronic lifelong problems for them. We in our rehab program will oftentimes see people that had their brain injury 30 years ago, and they're still dealing with some of the issues and symptoms related to that even though that injury and the acute medical care related to it is quite distant.

There's a whole variety of symptoms and problems that happen with this. I should have said this earlier, but as part of this talk I'm not going to go into the pathophysiology and the mechanics of acquired brain injury, traumatic brain injury, that's a whole other talk and an important one. But I do want you just to focus on here's some of the common-- this is not an exhaustive list, but here's some of the more common problems. This is actually from several sources, both just our own clinical experience-- if you do any review paper on brain injury most of these things will be listed.

And these are the neurobehavioral problems. This doesn't include some of them might have hemiparesis, gait problems, upper or lower extremity problems, that kind of thing. This is just the neurobehavioral problems, and it kind of covers the gamut of everything. It's memory problems, personality behavioral problems, impulsivity, inappropriate behavior. It makes it kind of hard if you have even a few of those difficulties to live your life. Just imagine if you showed up tomorrow and you had some of these problems. It would be hard to function, it'd be hard to do your job, hard to maintain your relationships. Hard to do a lot of things.

Some people would say, well, I know several people that have these problems. Of course, a lot of these are present in the normal population. But hopefully not to the degree to which they disrupt everyday life. And a comment families will often make is, gee, this person-- my husband that had this injury, he's more like himself than he ever used to be. Meaning that he was always opinionated, but my goodness, now he just doesn't shut up. He shares his opinion with everybody and in circumstances where it really alienates him from other people and makes it hard to live life.

Just to talk about what we do here at Mayo Clinic in terms of brain rehab, this is my colleague, Dr. L. Brown and our medical director has a whole variety of slides, and he kindly lent me a few of them. This is our line of service which is located in St. Mary's-- I still want to say St. Mary's Hospital, I don't think I'll ever be able to say St. Mary's campus, but you know what I mean-- that all the entities are located, both inpatient and outpatient. So I come over here for lectures most of my days over at St. Mary's.

What I'm going to focus on and what's highlighted is our outpatient arena, where a lot of the more chronic-- obviously we do hospitalization, we do inpatient rehab. But for people with chronic problems, that is more dealt with typically in the outpatient arena. And so that's more what we're going to focus on there in terms of where this research comes from for the most part and where the discussion is.

As I said before in the introduction that Mayo is one of 16 NIDRR-funded-- National Institute for Disability and Rehabilitation Research-- model systems. We've been funded since 1998, which I think makes us one of the old guys. I think there's two or three. We get refunded every five years, very intense competition. And we've been fortunate to have been funded since 1998.

And that allows us to do a variety of things. Research-wise and clinical-wise we just had a meeting here last week where we had representatives therapists from all those model systems, and they came here and saw what Mayo does. We will have a meeting in Pittsburgh next year where the therapists will go there and find out what they do. So it's a way to do best practices with the highest ranked rehab departments in the country.

It also allows us to compare with how we do with other centers. So this is kind of our brag wall here. And as you can see, this is how Mayo Clinic and Mayo Clinic traumatic brain injury patients compare with four other centers that other top-- these are the top five. So of the 16, these are the top five. The other four shall remain nameless, we can't name them. But we can name ourselves. And this is the disability rating scale. And of course, the higher the score, the more disability, the lower the score, the less disability. So you want a low score on this scale.

We look pretty good. We compare favorably-- we're number one or-- in this scale, actually, number one for people who were followed up, who went through rehab here, and we're following them by phone at year one, two, five, and 10. We actually follow people 20 years and even further if they get that way. And this is part of the model system is to follow-- gives us funding to collect data and follow people fairly comprehensively in a variety of things, including this measure over a period of time.

Now there's some dropout rates, so that has to be taken into account. But the thing to notice from this graph in addition to that, gee, we look pretty good, is that there is a slight decrease from year one, two, five, 10, that people seem to be getting a little bit better over time. Now, there's a caveat there in terms of we don't capture everybody all those times. But that's encouraging. Another measure is the FIM measure the functional independence measure, which most rehab centers, I think there's going to be a switch to another measure in the coming years. But that's the nature of the most rehab centers use on the inpatient side to measure functioning. And that's the higher the score, the better.

So again, we're the blue bar on the left side. This is encouraging that if you're a patient and you come to Mayo Clinic for your brain rehab, we can say that we compare favorably to the other top five centers in the country. And last is the GOSC, which is the Glasgow Outcome Scale, which accompanies and was written by the same individuals in Teasdale that made the Classical Coma Scale score. And just an eight level measure of outcome from good outcome all the way to death.

And so this is the percentage of people that had a good outcome after their recovery. And again, you can see it's nice that, gee, the patients are improving over time. And that, again, we look really favorable there. So again, this is the time for us to brag on ourselves. But it's nice to know. And this is the advantage of being part of that model system that we can make comparisons to other centers in a way that isn't really possible, at least with that specific patient populations and rehab at this point.

This is a study that was done through the REP, the Rochester Epidemiological Project, by several colleagues here. Dr. Brown and James Malik, who was here until '89-- excuse me, 2008, rather. And this is important for a variety of reasons. There's a lot of talk at both meetings I go to and even in the popular press that if individuals that have a history of traumatic brain injury are not going to live as long a life. They're more at risk for dementing conditions later in life.

And there's all sorts of other things that happen. That's talked about commonly at meetings, oftentimes with clinical samples where, gee, all these people that I saw that showed up in my clinic, they didn't seem to live as long as whatever. So not controlled epidemiological studies, but just I've heard many people with good research credentials argue that, no, I'm convinced that people with this history don't live as long.

And perhaps, but in really one of the only one of its kind studies done at least in our country where looked at people epidemiologically was this study right here that actually just came out this year. And you can get it on the *Journal of Head Trauma Rehab*, one of the main journals in our field, and get it through the electronic journals in the library.

And what they found was this, is they actually went a step further than most studies. I'm going to say the term wrong, but I'll describe it. They didn't just compare to adjust it for age and other variables, you know, here's a brain injury sample, and here's people the same age, when do you expect them to die? But they took into account all the other things.

If you have a severe traumatic brain injury, the odds are pretty good, at least a majority of people will have a splenic laceration, they'll have pneumothorax, they'll have all these other things go on. And all of that, of course, can contribute to morbidity and mortality. What they did is control for all that, In a nutshell-- I'm not going to do the study justice other than to say that they really did a good job of controlling for other factors that could contribute to life expectancy beyond a traumatic brain injury itself.

So they had a genuine control group, a trauma group-- they had a brain injury trauma group and a non-brain injury trauma group-- in control, I think they even acquitted for an overall trauma score. And here's what they found is that in injury follow-up, the hazards ratio, they found 1.48 greater hazards ratio for the brain injury group than the non brain injury group. But what they also found is that if you looked at just the people up to six months, that was significantly greater than 7.13. And if you looked at six months or longer it was essentially the same, it was 1.05.

So the lesson from that study is that the risk of death is 1.8 times the control group-- again, with that specialized control group, not just the general population, but a trauma control group. But that greatest risk-- in fact, arguably the main risk, the only risk was during the first six months. And there was no increased risk for six month survivors afterward.

If Dr. Brown was here-- and maybe he is-- he'd be talking about this passionately, and I've heard him do this. Because this is not widely accepted. Because there's not much epidemiological research when we go to different meetings. People are convinced from their own clinical samples in their own rehab clinic or their department that that can't be true. But golly gee, using the [INAUDIBLE] it seems like this is as compelling as anything that's out there.

And just to reiterate-- and this gets to the idea of a chronic medical condition. The good news is that if you have a traumatic brain injury-- and this could include all severities, but many of these were very severe-- that and you survive six months-- you get through that initial hospital stay, perhaps ICU stay, rehab stay, initial follow-up appointments, and everything else-- that your life expectancy, at least related to that history of brain injury, is going to be what it would have been otherwise.

But the flip side of that is that means you're going to live a normal life-- oftentimes good thing-- with chronic problems. You're going to live a full life, but you're going to have the difficulties I mentioned earlier. The impulsivity whatever, at least in a subset of the population, with lifelong problems.

And then again, just to reiterate, the increased risk of death after TBI is due to external causes and exists only during the first six months. So yeah, there might be an increased risk, again, if you didn't look at all those good controls like they did, but it could be for other medical reasons. If you have a severe enough brain injury, the odds are good you're going to have some other kind of trauma as well.

Many of you have probably heard this name. I've had the pleasure of hearing Dr. Teasdale talk a couple of times. He and Jennett, of course, developed I think it was the early '70s in *Lancet*, the Glasgow Coma Scale score, which still is the most widely used measurement of coma in the world. And he's still in Glasgow. I don't know if he's still practicing, but he's still on the lecture circuit for sure.

But what I did here him talk in a meeting four years ago, and it was the International Brain Injury Association meeting, he developed the Glasgow Coma Scale score, but thankfully for those of us in rehab, he also has an intense interest in long term outcome. He's a neurosurgeon, but he likes to follow these people long term. He knows the literature, he does this, and he developed the Glasgow Outcome Scale score, as well. So he really has a very significant clinical and research interest in long term outcome, as well.

So one of the-- and I took a picture of this slide because I thought it was so cool-- is he really summarized-- I could cite you all sorts of studies, but he did a nice job of summarizing what factors-- and this is the title of the slide-- at one year-- these are people are one year after brain injury. So going back to the Epi slide, people that based on the EpiData, at least from here, they're likely to of a normal life expectancy. They're one year post-injury.

But what's going to predict how well they're going to do at five to seven years post brain injury? So many years later, arguably more of a longer term outcome. What's going to predict how well they're going to do? I don't know if anyone-- they need this to be interactive, but it could be. Anyone have a guess, anyone want to be bold today and say what might predict if people are going to do better? And by outcome I mean how independent they are. Are they able to work, are they able to live on their own, are they able to maintain relationships? Those kind of outcome measures-- I mean arguably outcome measures. Anyone want to guess which one would perhaps contribute to doing better or doing worse? Just yell something out.

**AUDIENCE:** Family support.

**THOMAS BERGQUIST:** Family support, wonderful one. Family support, excellent. Any other guesses? Dr. Thompson is an educated guess. We know he does this stuff, so any other-- be bold, come on. Age, OK, very good. Those both I think could be there in the mix. This is what he said in his summary, and it was based, I think, on his experience and just reading a whole lot of studies and writing some himself.

And people tend to do better when there is lower depression-- that doesn't mean lower incidence of depression, diagnosis of depression, although it could be, but lower rates of depressed mood-- lower anxiety and life stress. And people tend to do better when there is higher self-esteem-- I thought it was kind of cool that a neurosurgeon was talking about self-esteem, kind of fuzzy-wuzzy psychosocial contact that a psychologist like me would be talking about-- and better when there's better cognitive abilities. And people do worse when there's, on the other side, lower self-esteem, higher depression, anxiety, and life stress, and alcohol use. Now, they didn't include drug use I just think because there wasn't enough literature on that. But a more recent review of literature would probably include that, as well.

Now if we were to take all of us in this room, and we were to follow us five to seven years from now, and we were able to see how well we're doing with life, what things do you think might predict that outcome? Probably some of the same things. Maybe not to the degrees and whatever, but very similar kind of issues would predict who might be doing well and not doing so well.

Those folks that he was talking about had moderate to severe brain injury where they were hospitalized, they perhaps had neurosurgery. And that there's several studies-- and I just put two of them up here for purposes of illustration-- that talk about people with mild traumatic brain injuries often use we talked about the term concussion. And the idea that what factors might predict outcome in those groups.

And this is just two interesting things that these studies that I just find really interesting. This came out of TIRR, Texas Institute of Rehabilitation and Research in Houston and a history of stressful life events before the injury might predispose persons with mild brain injury to have poor outcomes.

So this doesn't mean that brain injury is stressful, though it might be. This means that someone that has that injury and has that in their history is likely to have a poorer outcome. Interesting thing. Because we're talking about functioning here, and we're talking more about-- so we'll get to explaining this in a bit.

And the other one is emotional risk factors, including overachievement, dependency, grandiosity, borderline personality traits, can compound symptom presentation of persons with mild TBI. More likely to have increased symptomatology, and therefore less good outcomes. So two studies that point to other factors beyond the injury itself that seemed to affect outcome.

So how do we understand or move to understanding the various factors which help maintain-- or explain, rather-- the nature of the clinical problems, direct treatment, and help us help patients have the best possible outcomes? Those few slides, my intent was is that there seem to be things beyond the injury itself that explain how well people do. And how do we take that into account?

Well, it's helpful to start with a model. This is an example of a bad model. I think this really came out of-- what was this now, something with climate change and carbon emissions. And the government went overboard. But we want a model that works, has some level of acceptance, and which helps all of us to understand, which it helps direct what we do, how we understand the problem, and directs what treatments we're going to give, and also helps us understand what the research questions are and how best to research it.

And this is that model. Oh shoot, I think I-- oh, I see what we did, OK. More clever than I thought. Well, here's the basic part of the model. I borrowed this from Dr. L. Brown, too, and I didn't realize he was so clever here. I should have known. But here's the basic model, and this is read at the WHO webpage, World Health Organization. So if you want this just Google them and you can find lots of stuff about this.

Now you've probably heard of the ICD-- ICD-9 and now ICD-10-- and that's what that is. ICD helps diagnose the health condition. But how many have you heard of the ICF before, International Classification of Functioning? OK, many but not everybody. Good, then we're hopefully going to learn something here.

Here's a measure of impairment, and we'll define these in a minute. But beyond impairment and the actual diagnosis based on the ICD, this model also incorporates talking about ADLs. ADLs are-- we'll have a graphic that shows it later, but you know can you brush your teeth, can you get dressed, can you use the bathroom, can you do-- kind of things, especially in an inpatient rehab setting that are the focus of rehab efforts.

And then measures of participation or life roles. Can I maintain a relationship, and I am able to relate to someone over a long term, be married, to have a significant other, to maintain relations with my family and be able to hold onto a job, and be able to complete my college degree? Or I'm able to just be in school at all. And those are the participation measures life roles. And then at the bottom, things that influence all of these are environmental factors and personal factors.

So what we're going to do here is-- and these are, again, right out of the WHO website-- is just kind of talk about what does this model mean? I think this is a crucially important model for all of us to know if we work in health care. And the WHO would certainly say that, for sure.

So what is functioning? I mean, that's kind of like what is breathing? A pretty obvious word. But here's how the model and the WHO defines functioning. Functioning is to live the experience of health. You have this condition. How do you live out with it? You have hypertension, you have diabetes, you have peripheral neuropathy, you have whatever. How does that impact your life? So it's not the test results per se, it's how does this impact your ability to go to the grocery store? How does this impact your ability to go to church on Sundays? How does this impact the ability to go to your kid's house on a Wednesday night for dinner?

Functioning is associated, then, with one or more health conditions, basically whatever health condition you have. And you know, I'm in my 50s, and the simple truth is the older you get, the more chronic health conditions you're going to rack up. That's just the nature of the beast. Functioning is not-- this is key-- not a direct consequence of a health condition per se, according to this model. It's not a one-to-one correlation. There's other intervening factors that come into play that help explain what's going to happen. And those are the crucial parts of this model.

And functioning right here, the last point, is a product of interaction between a health condition and contextual factors. Who you are, where do you live, what are your relationships like, how educated are you, and a whole number of other things. So does this make sense? You know, functioning. We're not talking about impairment here, we're talking about functioning, diagnosis.

Again, this is right from the WHO, so I'm just, I guess without maybe meaning to, I'm promoting their model. Using that model along with the diagnostic model, the ICD, they're designed to be used together and should be used together to describe both the health condition and its impact on functioning. So you can diagnose the condition but you can't-- or at least you shouldn't-- talk about its impact on functioning without some reference to or at least understanding of this model, WHO would argue.

So here's the different components of it, positive meaning they work to enhance functioning and negatives mean they work against functioning. So the positive side is bodily functions, basic physiological and psychological functions. Things like your mood, things like your blood pressure, things like maybe test results, like an EMG result, bodily structures, activity. We talked about execution of a task or an action by an individual, and in participation involvement in life situation. I'm working. I'm going to school. I'm married. I have kids.

Negative are problems in a body function and structure, a significant deviation or loss in that. I have hypertension. I have diabetes, my blood sugar is out of whack. I have some other condition, I have peripheral neuropathy, I have something else that is impaired and we can show it on multiple medical tests. And it impacts the function of those body [INAUDIBLE]. And activity limitations are, because I have diabetes, I have peripheral neuropathy, I find it difficult to walk very far and difficult to drive very far. My father who was in his 80s, this is where he's at. That he only drives short distances because he doesn't like to drive when he can't feel the pedals, and it's because of that that he can't feel the pedals.

Participation restrictions are because of activity limitations, and in part-- going back a step further, perhaps-- due to some medical condition, you have difficulty living on your own. Someone with enough chronic health conditions that impact their ability to get dressed, take their medications, whatever, may not be able to live independently. They might need someone to help them up, perhaps their spouse. Or if it's significant enough they might need to live in some residential facility altogether. But that would be participation restrictions. You're restricted in your ability to fully participate in the life role or life situation.

Is this making sense? A few head nods, OK. And then there's different components beyond that. We're talking about impairment, activity limitations, and participation restrictions. What they used to be called, and you still hear this language, was impairment, disability, and handicap. That lingo went out about 15 years ago, 12, 13, something. And now we talk about those other terms. Maybe political correctness, I don't know, but it's the same kind of idea. And the other components of the model, which again are integral to understanding functioning, are environmental factors. Physical, social, attitudinal, environmental, in which people live and conduct their lives and connect as either facilitators or barriers.

And these have changed over time. I mean, this room, I know there's a door over there, but it used to be 30 years ago that it was hard if you were in a wheelchair to get in certain buildings. And there's many other countries where that's still the case. That thankfully has changed at least in most settings in our country and many other places, as well. But that would be an environmental factor that limits your level of independence. Yes, you perhaps have a spinal cord injury, had a stroke, and you're in a wheelchair because of that. But it's that environmental factor that limits your independence. If everything is accessible, you still have in a wheelchair, but your level of independence will be less limited because of that environmental change.

Personal factors make up someone's life, who they are, how they value certain things. What do they think of themselves? What does their family think of themselves? What is their role? Are they directing something or are they someone that is more in a role where they following the direction of others, we'll get to some examples here in a minute. And barriers are something that an increase in the severity of disability, and facilitators, neat thing, actually improve or in some cases maybe eliminate the effects of the disability altogether. Because factors might be such that this person has this condition and a potential disability, but it doesn't really play out day to day life because these factors are such that they prevent it from happening.

ADLs, probably know what this is, just some common examples. IADLs are the more kind of complex ones, the more basic ones are the ADLs again. And in a rehab world, these are the things that are more commonly the focus of inpatient, but often enough outpatient rehab stay.

This is really the hardest one to define. The restrictions in participation. And this is, again, the whole idea of a life role, individual with participation restrictions will be unable to stay in the roles to which he or she is accustomed or to attain those which might otherwise aspire. OK, yeah, I didn't I think of a young person that had a traumatic brain injury, and they were able to turn pretty independent. But their goal was to go to college or go to med school. And yeah, they were independent now, but that thing to which they aspired they perhaps weren't going to be able to achieve.

Reduction in ability to participate in life role to which they attach value, and that's the thing is you might value something different than I value. This is very individualized and consequently very hard to measure. So there have been very valiant attempts to develop a scale of participation, but it's really hard to do. Because what your participation is not necessarily what mine is. It's so individualized that there's-- hard to develop a standardized scale that measures everything.

The other thing is, these are only really experienced when the individual attempts to perform activities in their own context. We've had patients come to Mayo Clinic from different settings, different cultures, and they're in a wheelchair around here, and I've heard them tell me that when I go home this is going to be hard because I won't be accepted there. And here not that everything is wonderful and rosy, but there could be some cultural differences which make being in a wheelchair much more difficult and stigmatized than it is here. So it varies on the culture, it varies on the situation, and maybe even within a culture in the generation.

I know my kids-- I worked with two psychologists when I was in Chicago, both of whom were to different degrees quadriplegic. They were in wheelchairs, they able to drive with special adapted equipment. And I think if that would have been reversed a few decades, they would have got a lot of stares, and they probably wouldn't even have had a van that was specially equipped. But my kids when they saw them they were like, wow, that's cool. They just thought it was the neatest thing that they could get in this car and go anywhere they wanted. And they didn't talk about their disability, they just-- that was-- because they were used to, in part because we have a family member, they were used to seeing people in wheelchairs and it wasn't any big deal.

And again, the last point this is most meaningful to patients. In other words, you can do all these wonderful things. But if an individual, because of some health condition, isn't able to participate in the life role that they value, what does that mean? And this is when people will say, gee, you're getting better, you're getting better. I mean, we'll say as therapists in rehab setting. And they'll come back and say, no I'm not. And they are getting better. But what they mean is, I can't do what I used to do. I can't work like I used to work.

And so that's what they're talking about, that I can't do this thing that is really the most important thing to my life and gives me a sense of value and reason to get up in the morning. I don't care how much better I am, I can't do that. And that's what they're saying is that they're not the same thing they were.

And just some examples here to kind of put a little meat on that. As facilitators, just talk about a family. And these are terms, if you're familiar with the family therapy lingo, we talk about adaptability and cohesion. In a family system that with levels of cohesion adaptability which leads to ability to change roles and support the person. And they-- OK, dad's kind of out of it for a while, so we'll step up to the plate and we'll kind of help out for him. And this is hard, but we can do this.

And then you get another family that everybody has their thing, and nobody ever does what anyone else does. And if someone gets injured they kind of don't know what to do because they're so entrenched in their family roles that it's really difficult to change roles. And I'm not trying to be judgmental here at all. But families differ that way, and one family will have-- one person with a one kind of family versus the other will have a more or less difficult time or a different outcome for that reason. So that gets back to the family support idea. It's more than just support, it's kind of what's your family like?

And work. Work in a setting which everyone's expected to share responsibilities, this is kind of the ideal work setting. Hopefully we all work in a setting like this. Everyone is aware of everyone else's life circumstances, they get together socially. I know your kids' names, I know where they went to college, I was at their wedding. I went to their graduation party. We had Jim last year, his wife had breast cancer and that was so terrible. We brought him meals for a while, and we even got together and pooled some of our sick time so he could take some extra time off.

And if that's Jim's work experience, Jim's going to-- Jim, then, or somebody else, rather, has some injury or illness and they have to be off work, and they want to go back to work, that setting is probably going to be supportive to a large degree because they just do it, and it's just part of it.

Whereas if you work in a work setting, maybe you work from home. Maybe you have your own business. You're just out by yourself, or you work in a very cubicle kind of-- a Dilbert kind of world where everyone does their own thing in their own little cubicle. And the actions you have a very cursory and whatever. If you need to go to back that kind of job, makes sense that that's going to be a little different thing than if you have a work setting-- you might not like your coworkers knowing what you're doing, but boy it sure makes it nice when you might need their help.

And just some other things about individually. And again, these aren't measures of pathology, these are just normal variations between who we are. If you have someone who is open to change, is this different? I can do different. Different's OK. And they're open to receiving help and assistance from others. That's no problem. As opposed to someone who normalcy is the same as things never changing. Other words, the only time I feel normal is when I do the same thing I've been doing for 20 years.

That's great, but that isn't always possible, especially if you have a chronic health condition that impacts your ability to do that. And I've had this discussion with people many times who independence is never receiving help from anybody. That's my definition of independence, as opposed to receiving help from somebody helps me be independent. A little bit of a semantic shift, but a very important distinction.

And sometimes, if it gets to the whole model, that difference can be the key element to successful outcome, is that that person shifting from I guess it's OK to have help every now and then. Because if they do, then they're going to be able to perhaps stay in their own home. But if they don't accept any help, and the only way they can live is to be on their own, then maybe that's not going to work.

And here's the key element of this. Here's the rub, is that I guess we do these same things again, don't we? That most of health care and diagnoses-- and this is how it should be-- is correlating some measures of impairment, some findings, imaging studies, blood studies, this, that, the other thing, with some diagnosis, or maybe several diagnoses. And that's as it should. But that's what it is. But that doesn't necessarily take into account all these other things I've just reviewed with you.

So the rub is is that if we really want to understand especially a chronically ill population, like chronic traumatic brain injury, that term I used earlier, we'll understand how well they're doing in day to day life, what's causing them frustration, and what we therefore intervene with and rehabilitate that we really need to take in account all these other things beyond a traditional diagnostic model. Does that makes sense? And anyone that's done this, we'll just know you're not going to understand what's going on, you're not going to get the best outcomes until and unless you bring all that to bear.

And taken to its illogical extreme, if you really focus on it has to be this diagnosis or that diagnosis-- and sadly I've seen this over the years-- is that if somebody shows up, and they have a medical condition, and it can't be explained by the diagnostic model per se, or the tests that they've been given, or the measures of impairment like we talked about before, that you can get these false dichotomies. Well, if it isn't neurological, then it must be psychiatric.

And if it isn't organic in the brain organic sense, then it must be functional in the psychiatric sense. Or worst of all, if it isn't a real problem, then it must be malingering. And that's just-- human beings are not easily put in boxes, and this is just bad medicine. I mean, that just doesn't work that way. Yeah, there are people that mangle, and yeah, there are people that present with neurological symptoms that primarily have psychiatric problems. But in general this way of looking at things just doesn't work. And it doesn't describe the population.

So if this model is accurate-- and by that I mean this model that incorporates all these things as ICF model-- our clinical experience and research findings should support it. I mean, we should be finding things that are consistent with it. So what I'm going to do next is try to do just that, some studies that we've done over the last eight years or so that look at this whole idea of cognitive rehab, which is a major component of acquired brain injury. And does that seem to inform us as to the validity of this model?

Well, one thing is maybe done some not so smart things in my career, but one of the smart things I did 20 years ago was to join this group that's basically been not the only, but one of the main groups that's written practice standards in the field of cognitive rehabilitation nationally. And there's three and soon to be a fourth review paper looking at the literature in this area.

And what they came up with through 19-- or 2008, rather, is 370 of over 1,500 papers that we reviewed that actually met the standard to speak to the issue of does this cognitive rehab thing work, and if it does what works? And cognitive rehab is basically kind of what it sounds like it is. It's rehabilitating cognitive functioning, behavioral, emotional changes that often occur after acquired brain injury-- it's kind of the list of neurobehavioral changes I listed earlier-- and help impact them in such a way that they do not create as much disability over time, again, using that kind of chronic health model.

And there were 370 that met muster that were at least somewhat controlled study, and 60 of them were a class 1, which means an RCT kind of was set, a randomized controlled trial. So not too bad. I mean, if you look in other areas of medicine, it compares pretty favorably. There is actually a lot of literature that supports those kind of interventions.

But the take-home message is this. Is here there were standards, guidelines, and options. And standards are based on one or more class one study. And I purposely put italics or the words that I wanted to do, and here's where they are. Functional communication deficit, strategy training. And this is just based on the studies. We're just taking these aggregated studies, and what do the studies say? What's the intervention and who is it recommended for?

But the terms I want is strategy training. What is strategy training? What strategy training is, you have something that doesn't work as well-- you're impaired in your memory, you're impaired in your attention, you're impaired in your behavior control, you're more impulsive, whatever-- and you develop a strategy. Does that get rid of the impairment? No, it does not. You develop a strategy to help you compensate for the impairment so your memory isn't as limiting to you as it would have been otherwise.

And that's what the literature seems to say. The published literature suggests that it's strategies, and using them, and developing compensation techniques. And self-management strategies have the greatest likelihood of decreasing the disability after acquired brain injury. And in these reviews-- it's broadened over time, but it started out with stroke and traumatic brain injury. It's extended to other areas including a variety of other conditions under that umbrella of acquired brain injury.

But those are the key words. In other words, if we were not changing impairment, but we are changing other things-- here's a few more studies that speak to it well. We did a series of telerehab studies here that looked at, again, using a cognitive rehabilitation model using an evidence-based thing there such as were listed on the other studies. And what changes, and what doesn't change, and what seems to correlate with change were kind of one of the questions we answered. It wasn't my original intent, but we found out some things kind of incidentally.

And here's the summary from that one. I don't know if I'll be able to read all this, but we had 15 persons in an RCT. It was a wait list versus just the actual strategy development condition. I looked at is remotely provided cognitive rehab after moderate to severe brain injury. And there was clear and proven level of independence. The interventions seem to do well in a independence level and how independent were you, so a kind of participation measure.

But the other thing we thought is interesting is greater independence was correlated with more frequent strategy use at both baseline and follow-up treatment, but there was no relationship between how independent somebody was and cognitive impairment. We didn't change the impairment, we changed their strategy use, which in turn helped them be more independent.

So the impairment continues. And again, this idea of chronic traumatic brain injury. You're not changing the impairment, you're not changing diagnosis, for that matter. But you're working at a level that they're able to do things like remember to take their medications. They're able to do things like remember to call back their boss, remember to do things like remembering their wife's birthday by using these strategies.

Another study we just looked at a correlation between a group-- and this is too noisy here-- but again, looking at impairment and functional measures and this whole idea of strategy use. And again, the degree of cognitive impairment was not associated with how much compensation or activity limitations. Other words-- yeah. But less frequent use of compensation strategies associated with greater participation ratings of mood and memory difficulties.

What does that mean? That it's not how impaired you are based on all these cognitive impairment measures we can give you that predicts how independent you are, and how much emotional distress you rate, and how much memory problems you rate in day to day life, or your family rates, it's how much you're compensating for it. So it's the person that has strategies in place and is able to remember things that way. It's the person that's compensating for those impairments and causing them to be more independent in their activities, and therefore able to achieve these life roles that does better, even if they're impaired. So impairment tells you, yes, that they had this condition perhaps, but it does not tell you how functionally independent they're going to be.

And this has to do with satisfaction. Want to make sure Dr. Thompson saw that study because his daughter's on there. We had yet another sample-- we had three different samples in three different studies. And this again was an RCT, in this case it was a diary, so kind of a sham intervention versus actual strategy development condition. And again, providing remote cognitive rehab, these are people using an instant messaging system. They're doing the same evidence-based cognitive rehab. And the person that's had greater strategy use at baseline reported higher levels of satisfaction with the intervention at the end of the study an average of eight months later.

So the people that go into this-- this is interesting-- that are already kind of amenable to using strategies to compensate for their problems, and they have treatment for an average of eight months, long time later, those folks are much more satisfied with it. So what this tells us is that this is a hard-- kind of points I was making earlier. That people that come in there and make me better, I don't want to have this problem anymore, make these impairments go away, that might be tough. As opposed to I'm already in the habit, or at least I'm amenable to using some strategies to help me. I'm going to be much more satisfied once this treatment is done.

So you're more satisfied because you're buying into, or at least you're receptive to the treatment model. And that's a lot of what we do is getting people that, boy, I wish we could make this go away for you. But what we can do is help you develop some strategies that will lessen the impact of this on your day-to-day life.

And this is another from our day rehab program that we've had here in the past. Just look like the relationship of goal attainment to outcomes of vocational independent living one year post-discharge, even. So vocational, how independent are people in terms of their work life, and how independent are they in the community?

And just the first point is that these goals are really functional self-management goals. The goals aren't my memory is going to be better, my goals are, I'm going to be consistent at using a planner so that I can write down, check off, and record activities in day to day life to allow me to do x, y, and z. Those are the goals. And I'm going to do this so I'm not as impulsive, I'm going to do this so if I get stressed I can cope with that stress. And achievement of those goals is associated with increased levels of vocational functioning and residential independence one year post follow up.

So even though they're one year post follow up, they've achieved goals that are focused on, again, this idea of strategy training and everything else, they're more independent later. Has the brain injury gone away? No, it has not. Are they still impaired if we measure them with various kinds of cognitive and neuropsychological tests? Yes, they are. But their disability is less, their activities are less limited because they are applying these strategies in day-to-day life. And there's a difference between those that met their goals and those didn't, but there was no other difference between the groups. Same demographically, same in terms of other measures.

So here is, actually, I think why I was asked to be here. And this was a poster that we did last fall just to kind of end this up that looked at, just as it says, impact of mood on outcome during post-acute what we do actually day in day out in our brain rehab clinic.

Again, Mayo Brain Rehab Clinic, we had 78 persons with complete data of 120 that were referred. I'm fairly confident to say that the ones we don't have complete data for don't look necessarily different from the ones we do have complete data for. This was a time period of just over a year between August of '11 and December of '12. And all these folks received based on clinical need interdisciplinary rehab that typically included occupational therapy, speech language pathology, in some cases physical therapy, and a few other team members, as well.

Treatment lasts an average of five months, and then we had measures given both at admission and discharge. Here's, again, the diagnoses for traumatic brain injury, but also a whole lot of people with stroke and other conditions. Other conditions could be things like anoxic brain injury, could be brain tumor, or other things. Fairly white sample reflects our area of Southeast Minnesota. More males than female, but pretty representation. Here's the education again

But these are our different measures we used, and I'll explain those. But the MP2I is a disability measure if you will, and it's a t-score of-- this will make it more clear when I get to the point, here's those measures in particular. You're probably with the PHQ-9, the main measure of mood state, and the vocational outcome scale and independent living scale are just that. Are they back to some kind of community-based employment or not, or are they in living independently or not?

And here's our outcomes. Another thing to know is that people get better. If you look at that breakdown there, the PHQ-9 from the original scale developed is that it's considered mildly elevated if it's a score of 10 or greater. And about a third almost of the folks that come to us, if people have acquired brain injury severe enough that they get referred to rehab, so they're having some problems. But about a third have an elevated score in the PHQ-9. Nicely less than half of that by the time you're discharged, which an average of a few weeks or months later, that goes down significantly. So we were talking about they're getting better, they're feeling better. They're reporting less emotional symptoms over time.

And then the Mayo-Portland is a measure of disability. How impaired are they? And the higher this score, the more disabled. But the way we did it here is, how many have less than a 40 t-score, which is less than very mild problems? And only a third, 31%, have only mild problems at the beginning, 70%-- over twice as many percentage-wise-- have only mild problems at the end of treatment. So this is nice to know. We're doing something and it's really working based on an objective scale.

And again, outcomes in independent living. That goes from 58% to 85% in terms of people that are living independently over the course of treatment. And outcomes with vocational. Now, a lot of the folks aren't going back to work. So we'll never get 80%, 90% on this, because a lot of people, especially the stroke patients, are retired and they have no goals. But of those that do, which is a significant minority, there is a huge increase here in terms of them getting back to vocational things over the course of treatment. Arguably a good thing.

So whatever we're doing with the different things we're doing, these are the kind of outcomes that any one of us and our patients would want. Are we impacting their independence, are we impacting their functioning? And to look at that, it's like, OK, so all those things are changing. How is mood impacting those outcomes? and this was kind of the key little finding we had from this presentation.

M2PI is given because that's the measure of disability at the time of entering treatment. So we want to covary that out. And the PHQ change, the mood change, was found in regression analysis that that predicts independence at dismissal. There is a relationship there that there seem to be independent predictive power of improvement in mood with increased level of independence. And these scales really measure different things. One is how independent you are, and the one's asking a variety of questions about your mood.

Similarly, there we come with a similar thing, employment. That, again, controlling for level of admission baseline disability, that improvement in mood also seemed to predict employment level, a level of employment functioning rather at dismissal. So first of all, it's nice to see that there was significant improvement in all outcome measures over the course of treatment. I didn't provide any stats for that, but those are significant.

There were no differences between the persons with different causes of acquired brain injury in these outcome measures. Those three basic groups, they're all getting better. And, yes, we want to know someone's diagnosis, and yes, there are certain things that stroke patients will need that TBI patients will not. But when in a rehab world you're really focused on whatever the causes of the disability, we're treating the disability. We're treating the functioning. And we want to help people get better. So yes, we know their diagnosis, but this is what we like to see. Well, whatever you're coming in the door with, we're going to focus on what you're having trouble with, and we're going to help you get better as best we can because of it.

And improving the mood, as I already said, was associated with improvement in all major outcome measures-- functioning in general, but also with those outcome measures of vocational independence and living independence. So based on this finding-- and this was just our normal clinical data that we collect in part of our everyday practice. So I think it didn't require any funding to do it. We just kind of do it in what we do every day. Improvement in self-reported mood over the course of our post-acute outpatient rehab was associated with increased participation-- participation being things like independent living, and vocation, and vocational status, as said.

And these results point to the importance of mood with successful outcome after post-acute rehab. Now, we can't say, does the improvement in mood cause the improvement in those outcomes? Or the fact that you're going back to work, does that help you to feel better? Hard to say that with us. But at least we know those two things are associated and kind of that whole idea we want to take all these factors. Want to look at these things really holistically and take them into account.

So here's from everything I've said-- and we're running out of time anyway-- what does this mean? The model, the stuff we've summarized, the findings I put up here admittedly in a rather quick fashion. While necessary, measures of impairment alone are not sufficient to account for a level of functioning and treatment planning in persons with acquired brain injury. I dare say that that could be said probably of other patient populations as well, but I know this one, so I'm going to stick to this.

The ICS model-- and I'm not here to-- they're not paying me to promote this, but it's a model that's out there, it's widely accepted internationally, and it incorporates all these things, or something like it perhaps that will be revised in time-- which incorporates measures of activity participation as well as in factors impacting each of these like those personal environmental factors is more likely to give us that information which hopefully is necessary and sufficient to accurately assess, effectively treat, and in a research way of thinking, fully investigate persons with acquired brain injury, and again, hopefully other patient populations, as well.

I should add that in the ICF model, you can quantify the diagnosis, obviously, in the ICD, and you can quantify the activity areas. But there's no system as of yet how to quantify these individual factors, the environmental factors, because they're so individualized. But the goal is to try to do that over time.

So that's all I have to say. And I was going to list names of the Mayo Brain Rehab team, there's some of you there. But I know I would forget somebody. So I'll just thank everybody in aggregate, because it wasn't because of them, I couldn't do this, and I couldn't come here today. So thank you very much.

[APPLAUSE]