

INSide the OUTcomes: A Rehabilitation Research Podcast

Episode 10: The Midwest Regional Spinal Cord Injury Care System at Shirley Ryan AbilityLab

SHARON PARMET, HOST:

Welcome to INSide the OUTcomes: A Rehabilitation Research Podcast from the Center for Rehabilitation Outcomes Research at Shirley Ryan AbilityLab. Today I'm speaking with Dr. David Chen, the George M. Eisenberg Chair of Spinal Cord Injury Rehabilitation, and Project Director of the Midwest Regional Spinal Cord Injury Care System, also known as MRSCICS at Shirley Ryan AbilityLab. MRSCICS is funded by a grant from the National Institute on Disability, Independent Living and Rehabilitation Research. Welcome to the podcast. Dr. Chen.

DAVID CHEN, MD:

Thank you, Sharon. I'm pleased and honored to join you today.

SHARON:

Well, let's get started. It's kind of a mouthful, the Midwest Regional Spinal Cord Injury Care System, MRSCICS at Shirley Ryan AbilityLab. Can you just tell us what that is? Are there other model systems? And how does Shirley Ryan AbilityLab's model system fit into the larger model system universe?

DR. CHEN:

Well, I guess to be formal, MRSCICS, as we like to call our model system, is a leading center for innovative integrated, interdisciplinary research and clinical care for persons with spinal cord injury. And we have been in existence as a model system, except for one six-year period, since 1972. And so given the length of time and duration that we have been a model system, I think it's remarkable that, you know, we don't often look back on how we came into existence and how we have fit into the whole national, if not international care of persons with spinal cord injury.

The Model Systems program came into existence, really, the first center started in 1970, in Phoenix, Arizona, and two years later, five original centers, with our center as one of them, were established. And ever since that time, pretty much every five years, there is a competition to become a model system center. And I think what that does is it shows the dedication, the focus of these different health care centers and rehabilitation centers, trying to improve and advance the care of persons with spinal cord injury.

SHARON:

So, what is MRSCICS? Can you give an overview?

DR. CHEN:

Well, there's probably three main responsibilities of all the Model Systems Centers.

One is to provide comprehensive clinical care for persons with spinal cord injury. And I think as the Model Systems Program has continued and progressed, a lot of the treatment paradigms that we have come to believe as standards of care, a lot of that has developed and been established by much of the work that has been done in many of the Models System Centers. So advancing care for neurogenic bladder, neurogenic bowel, prevention and treatment of skin and pressure issues, improving and advancing rehabilitation care for neural recovery, and functional recovery in persons with spinal cord injury. A lot of that has come about because of things that we have discovered within these Model Systems Centers, and changes that we have made to how we treat these different issues related to spinal cord injury. So that's the clinical care.

The two other main responsibilities for these Model Systems Centers is research. And again, the over 50 years that the Model Systems Program has been in existence. There has been research that has been done by each of the centers that have been part of the Model Systems Program that have focused on different issues unique to spinal cord

injury. And again, a lot of that research and the outcomes and the results of that research have helped to develop innovations in treatments for those particular issues.

And then the third issue that is probably one of the most important of the Model Systems Program is contributing data to the National Spinal Cord Injury Model Systems Database. And this is a unique database, it is for spinal cord injury, the largest in certainly, in terms of duration and one that has been the longest in existence that has collected very large amounts of data related to injuries and demographics of persons with injuries and injury characteristics, different issues that individuals who have sustained spinal cord injury have experienced, and then how these individuals have progressed along. This is a continuous database and we attempt to follow individuals over time to see what these individuals have experienced as time goes on after their injury. In fact, there are individuals now who have been enrolled in the database since 1973, when the database was established, and who are still being followed to this date. And what we learned has helped determine new ways of treating many of these issues.

SHARON:

So, it sounds like the Model Systems have three kind of main areas, clinical care, research and the National SCI Model Systems Database. I want to talk a little bit more about how does Shirley Ryan AbilityLab and MRSCICS contribute to the National Spinal Cord Injury Model Systems Database? What does that look like on the ground?

DR. CHEN:

Sure. So over the almost, you know, 50 years that the database has been in existence, there have been occasional adjustments in terms of the data that's collected and characteristics of injuries and demographics and in many of the variables that are collected over time. But essentially, what it comes down to now is there are basically two forms that we broadly divide data collection to: there's a form one which we use to collect data related to how persons were injured and the characteristics of their injuries and how they took place. And a lot of the acute care and acute rehabilitation information related to their spinal cord injury.

So from the time that a person is injured, to when they are discharged from their initial rehabilitation hospitalization, that makes up what's called form one. So that's a large volume of data related to, again, demographics of injury in the early care of these individuals. Form two is the long term follow up of these individuals. And so the first form two collection is one year after injury. And then after that, individuals are contacted every five years in order to collect again, data related to what has changed in those five years or.

In the case of the first-year follow up in the first year after their injury in terms of medical complications, changes in rehabilitation outcomes, or what they have been receiving from a standpoint of care, medical complications, changes in their neurological condition. And so a lot of the long-term outcomes and changes that we've seen over 50 plus years in persons with spinal cord injury has come about from data that's collected in form two and as we see these trends and changes over time.

SHARON:

About how many people does Shirley Ryan AbilityLab enroll into the database in an average year?

DR. CHEN:

In terms of form one, we enroll about on average about 90 to 100 individuals with new injuries, which makes our center actually one of the leading contributors to the database, probably one of the top three in terms of numbers of individuals, and that is sort of reflective in the large number of individuals that we treat with different ranges and variety of spinal cord conditions within our rehabilitation program.

SHARON:

What kinds of researchers can access this data? Are they available to researchers outside of the model systems?

DR. CHEN:

Actually, that's a great question. Because in the last, I may be a little bit off in this, but in the last five years or so, you know, the availability of the database has opened up to the, to the, I guess you could call it the general public. So individuals who may not necessarily be a part of an active Model System Center, do have access and can request access to the to the database through the National Spinal Cord Injury Statistical Center in Birmingham, Alabama. And a lot of individuals over the last five years have actually approached the Center and made requests seeking access to the database and the information that's within that database. And that's, I think, terrific. That just gives so many more clinicians and researchers access to the voluminous amount of data that's within that database.

The whole goal of the database and why the data is collected is to understand over time, you know, how have spinal cord injuries changed, how do they take place, how has that changed, have prevention strategies been successful in reducing the number and types of injuries and then over time, seeing what individuals who have sustained these injuries experienced over time and, and do the treatment paradigms that we have created partly from the database, and partly from our, our understanding and role as a as spinal cord injury treatment center, has it been successful and effective in trying to reduce complications, and therefore, you know, increase the, you know, the quality of life and the, you know, the age aging of individuals with spinal cord injury?

SHARON:

Right. So you're able to identify trends over time, are the treatments we're providing working? Are perhaps public safety campaigns having an impact in this way? That kind of thing?

DR. CHEN:

Exactly. Yes.

SHARON:

Let's talk a little bit about the research that MRSCICS takes part in. I believe that when you're a Model System, you have a research project that you lead internally, you take the lead on it, but you also participate in other research projects that are taking place at other Model Systems. So can we talk about first the lead project at Shirley Ryan AbilityLab through the Model Systems?

DR. CHEN:

Sure. So as you said, you know, when one applies to be a Model Systems Center, one of their requirements is that you include what we call a site specific project. So this is a research idea or research project that is going to be done just at your center. So oftentimes, you'll see Model System Centers, like us will find an area of focus that's comes about because of what we may do in our center here. And then also, what we do as a Model System Center is we may lead a what we call a collaborative project or a multi-center project, where we may include, you know, at least two other Model System Centers in conducting that particular research. And the advantage of that type of research is, you know, it allows us to take an idea, but rather than just do it within our center, to take advantage of other centers, the numbers of individuals that are treated at other centers to try to increase the subject numbers, the population size, to hopefully, you know, improve the quality of the research that's done. And obviously, the outcomes.

And so our site-specific project is one that's entitled, improving adherence to exercise guidelines, using smartphone based technology and E coaching. So, you know, this is a project in which, you know, as there has been advances in smartphone technology, and, you know, electronic coaching, does that enhance or improve individuals with spinal cord injuries, advances or adherence to exercise guidelines. That's always been one of one of the sort of frustrating aspects of rehabilitation, you know, individuals go through inpatient rehabilitation, then transition to day rehabilitation care, or outpatient care. And then after that, there's always the question of, are they following through or continuing to adhere to, you know, different therapeutic exercises and activities that we believe are enhancing their functional recovery? We just don't know. And so does the availability, again, of these smartphone-based technology, and E coaching add to the benefits of therapeutic exercise that have been taught to these individuals? So that's, that's our site-specific project.

Our second project that we're a lead on is a little bit more scientific and a little bit more looking at a potential predictive value of symptoms that come along with spinal cord injury, and their different neuro humoral factors that are within the within the human body. And that's evaluating the utility of spasticity and BDNF in predicting neurological and motor functional recovery at spinal cord injury. And we're a lead center in this particular project. And it's a collaborative project that also involves three other current Model System Centers.

SHARON:

So why don't you break that down a little bit for us? What does spasticity mean? And what does the molecule BDNF, what is that? What does that represent to a researcher?

DR. CHEN:

So, spasticity is a sort of common secondary condition related to spinal cord injury. And in some situations, it's a negative aspect, because it may cause issues with discomfort or interference with positioning and may interfere with sleep in an individual who has an incomplete injury and has some residual neurological function, it sometimes can interfere with activity. So on a whole people oftentimes think of spasticity as a negative aspect, when in fact, the presence of spasticity may actually indicate a more positive predictive value in terms of person's future, continued neurological recovery. So, part of this particular study is looking at and measuring and quantifying as best as possible, spasticity to see if over time, if individuals with different degrees of spasticity have a more positive potential neural recovery.

BDNF is a substance that is actually within the human body that we can, you know, by just drawing blood, we can quantify the amount of BDNF that is in a person's human body. And again, this is a little bit more I guess you could call it objective in terms of measuring the amount and the quantity that's in in an individual at various times after their injury. There has been some that believe that BDNF is a good indicator, again, objective indicator that may have a correlation with a person's neurological recovery after a traumatic injury.

SHARON:

So this study will look at spasticity and levels of BDNF in people with spinal cord injury to see are these good predictors of outcomes down the road in terms of neural recovery?

DR. CHEN:

Exactly.

SHARON:

Okay. What other projects does the Shirley Ryan AbilityLab Model System participate in?

DR. CHEN:

We're also involved in actually several other collaborative modules. One that is, you know, related to an issue that's very widespread is urinary tract infections, the presence of urinary tract infections, prevention of urinary tract infections. And so we're involved with a large collaborative study that's headed by the Model System Center in Washington, DC, that's examining urinary tract infections. And so trying to, you know, be objective in terms of just what is significant urinary tract infection based on the labs that we currently use, and our other ways of measuring the presence, or the lack of a true clinical urinary tract infection. So we can try to establish a little bit more consistently what's treated.

And prior to us being Shirley Ryan AbilityLab, we were the Rehabilitation Institute of Chicago, and we have been a Model System Center since 1972, except for one six year period, and it has sort of become sort of an accepted and established part of our, you know, our spinal cord injury clinical program and our research projects. And I think, you know, what it really shows is the commitment and dedication to spinal cord injury care and spinal cord injury research that Shirley Ryan AbilityLab has, you know, has determined is going to be an important part of the clinical care and the research that we, that we do as part of our program. And it's, it's certainly one that has, you know, created and

established innovative treatment paradigms, not only related to medical complications and prevention, but even for, you know, rehabilitation care, both new injuries and in individuals who have been injured for a longer period of time. So I hope it continues within our center here. I think it's a terrific aspect of our of our program for clinical program. And I think it's one that, you know, has been incredibly valuable in terms of advancing the care for persons with spinal cord injury.

SHARON:

Well, thank you so much, Dr. Chen for being on the podcast. It's been great talking to you and learning more about the Model System at Shirley Ryan AbilityLab.

DR. CHEN:

Thank you, Sharon.

SHARON:

This has been INSIDE the OUTcomes: A Rehabilitation Research Podcast. This podcast is supported by the National Institute on Disability, Independent Living, and Rehabilitation Research. This is your host Sharon Parmet signing off. I hope you'll join us for the next episode.