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Summer 2014: Applying Research Knowledge



Welcome to the Summer 2014 edition of CROR Outcomes! In this issue, you'll find updates on two dissemination projects funded by our Rehabilitation Research Training Center on Improving Measurement of Medical Rehabilitation Outcomes grant from NIDRR.

Below, you'll meet the instructors who have brought the Rehabilitation Measures Database into their curriculum. On page 3, we introduce two instructors who

have successfully incorporated the Clinical Outcomes Measurement learning modules into their classrooms.

Additionally, we'd like to introduce Jennifer Piatt, Assistant Professor and Therapeutic Recreation Internship Coordinator at Indiana University, who helped us develop the Clinical Outcomes Measurement modules, and Allison Todd, a project coordinator who plays an instrumental role in the success of the Midwest Regional Spinal Cord Injury Care System.

For more information about our projects and educational opportunities, please visit our page at www.ric.org/cror. And don't forget to "like" us on **Facebook!**
Allen Heinemann, Director

New Role for Rehabilitation Measures Database

The Rehabilitation Measures Database (RMD) is used by thousands of clinicians and investigators around the world every month to find the best way to measure rehabilitation outcomes in patients with a variety of conditions such as spinal cord injury, stroke, and brain injury.

Researchers at the Center for Rehabilitation Outcomes Research (CROR) in partnership with clinicians at the Rehabilitation Institute of Chicago (RIC) created the database with funding from the National Institute on Disability and Rehabilitation Research. The field of medical rehabilitation is constantly changing, and RMD needs to reflect the focus of new research.

To keep the content up to date, Jennifer Moore, PT, DHS, NCS, a RIC researcher and clinician who directed the development of the database, has turned to the academic world. She has established collaborations with 12 universities around the country that involve students writing summaries of outcome instruments as part of their class work.

Students benefit by learning about outcome measures and having their names listed as the author of their summaries on the website. In turn, the database gets new summaries that give clinicians and researchers valuable information about a measure's reliability, validity, and other measurement properties.

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Jennifer Piatt: Striving for Evidence in Recreational Therapy

When Jennifer Piatt was growing up in North Platte, Nebraska, she spent part of every Sunday visiting a great aunt who was institutionalized because of an intellectual disability. Her aunt was the happiest when she was in the recreation room where arts and crafts projects were laid out for residents. "I was in the sixth grade and I thought, 'Wow, people get paid for this.'"

Piatt went on to get bachelor's and master's degrees in recreational therapy and a PhD in the philosophy of leisure. Her specialty has taken her from California to Utah to Indiana and has involved us-

ing sports and recreation to help everyone from those recovering from a drug or alcohol addiction to adolescents with mobility impairments.

"The biggest satisfaction is seeing people being able to embrace and live the life they want without limitations," Piatt says. "We find out what they enjoy doing and we make it work in their treatment and rehabilitation. Everyone has a right to sports."



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Allison Todd Finds Her Own Path by Helping Others

All through high school, Allison Todd wanted to be a physician. But she developed a dangerous cardiac arrhythmia when she was 13, and she spent weeks at a time in hospitals with doctors trying to figure out what was wrong. By the time she was 17, she had a partial answer - a genetic condition that had likely killed her father in his mid-40s. Even though she was very young, she needed to have an implanted pacemaker/defibrillator in case her heart stopped.

Todd was so tired of doctors by that time; she changed her career plans and decided to major in international affairs at the University of Chicago. But a representative from the U.S. State Department and her own doctors told Todd that her heart implant made her too medically fragile for a foreign posting. So she shifted gears again and decided to enroll in psychology classes at Northwestern University. She mentioned to a fellow student that she was looking for a volunteer opportunity in psychological research, and the student suggested she check out the Center for Rehabilitation Outcomes Research (CROR) at the Rehabilitation Institute of Chicago (RIC).

Soon, she was volunteering 30 hours a week, interviewing people who had experienced a stroke, traumatic brain injury, or spinal cord injury about how environmental factors affected their quality of life.

“To my surprise, I liked being back in a medical setting. I wanted to know more about people and their lives,” she says. “Within the first week, I had an interviewee break down and cry during the interview’s social section. It was a case of her realizing what she thought other people’s impressions of her were since she experienced a stroke.”

Todd halted the interview and took measures to ensure the participant’s well-being. The participant, however, wished to continue. “She [the participant] took a couple of minutes to calm down and then she wanted to push through the interview



Allison Todd

because she knew the research was helpful. She wanted to help other people.”

Today, Todd works full-time at CROR as a project coordinator conducting follow-up interviews with people with spinal cord injuries. Her job is complicated by a six year funding lapse which makes it difficult to regain contact with those injured between late 1973 and 1999, some of whom haven’t been contacted by the hospital for 35 years.

Once Todd tracks down former patients’ whereabouts, she must ask them to re-enroll in the study before she can interview them. It’s a bit like being an investigative reporter. “Of the living persons, I can usually find seven or eight out of ten. But whether they will respond to phone calls or mailings is another matter,” she says.

Some people are suspicious. Others don’t see how their stories

could be useful after all the time that has passed. “I make sure they understand the risk. The questions get into quality-of-life issues. There may be some discomfort,” Todd says. “But I’m not here to twist anybody’s arm. There’s nothing wrong in saying ‘no.’ I just try to make sure they understand the importance of the research.”

Her health continues to be a major issue. In her early 20s, she was diagnosed with a painful collagen disorder that causes a host of conditions throughout the body, including hyper-mobile joints, fragile skin, and heart palpitations. That means Todd can dislocate a joint by simply twisting the wrong way as she did recently with her knee while riding a bus. Fatigue is also a major issue.

“On days when I’m really tired or rushing around, I will have to take a minute and pull myself back. Everybody in the office watches out for me,” she says. “Having that caring base is really important.”

Now that her health is relatively stable, Todd is looking toward the future and another pivot in her career. She is planning to become a genetic counselor, which she sees as a perfect marriage of psychology and bioscience. That would require a master’s degree in genetic counseling, something she hopes to get from Northwestern University while continuing to work at CROR.

“The whole place helps you with your perspective. It gives you a more flexible view of life and how it can be fulfilling. It breaks through the box we put ourselves in,” she says. “I don’t think I realized before the capabilities that people have when they experience hardships.”

Using Outcome Measurement Modules in OT

When Susan Magasi teaches a new class of occupational therapy students about research methods, she usually finds that many of her graduate students haven't spent much time in clinical settings. That makes it essential to bring everyone up to speed quickly on the importance of measuring the results of rehabilitation therapies. To do that, she uses training modules that were developed by the Center for Rehabilitation Outcomes Research (CROR) at the Rehabilitation Institute of Chicago (RIC).

The modules are PowerPoint presentations that take students through the process of selecting appropriate measures and interpreting results to inform clinical decision making. Some modules contain embedded videos of therapists assessing patients.

"We're trying to impress on them the importance of measurement in occupational therapy," says Magasi, PhD, Assistant Professor of Occupational Therapy at the University of Illinois at Chicago (UIC). "I find the modules do a really nice job of walking the students through a series of case studies that help them figure out how to select an appropriate measure for a target population and understand the measurement properties."



Susan Magasi, PhD

Magasi acknowledges that research methods can be a dry subject, but it comes to life with patient videos. One video shows a man who has had a stroke taking several assessments that measure cognitive function and balance. The patient predicts he won't have any problem correctly putting his daily pills in a pill-organizer box. But when the therapist asks him to do that as part of the Executive Function Performance Test, he makes mistakes that show he was overestimating his abilities.

"It's not intended to be in-depth training on administering the test, but the test is used as an example of clinical assessment," Magasi says. "They've done an elegant job of weaving in fact-based information with case studies." Magasi points to the potential benefit for the wide-spread adoption of

the modules across occupational therapy programs.

"Occupational therapy programs have different levels of expertise in outcomes assessment, so using a resource like the training modules can help ensure that students, regardless of where they receive their training, have a common baseline understanding of how to use outcomes measures in practice."

There are four modules, which were developed by Carolyn Baum, PhD, Professor of Occupational Therapy and Neurology at Washington University in St. Louis, and Joy Hammel, PhD, Associate Professor of Occupational Therapy and Disability Studies at UIC. Other contributors were Allen Heinemann, PhD, CROR Director at RIC; Jennifer Moore, PT, DHS, NCS, Clinical Practice Leader at RIC; Kirsten Potter, PT, DPT, MS, Associate Professor of Physical Therapy Education at Rockhurst University; and Jennifer Piatt, PhD, CTRS, Assistant Professor of Recreation, Park and Tourism Studies at Indiana University (see related article on page 1).

The modules start with an introduction to rehabilitation measurement and progress to applying and evaluating measures in clinical practice. The fourth module addresses institutional barriers that therapists may encounter when trying to integrate measurement into their practices.

The training project is funded by RIC's Rehabilitation Research and Training Center, which was funded by the National Institute on Disability and Rehabilitation Research to improve the measurement of rehabilitation outcomes. Several professors at UIC volunteered to pilot test the modules.

Clinical Assistant Professor Robin Newman

is one of them. Newman, OTD, used the modules in a course called Human Structure and Function. Her class enrolls first-year occupational therapy students who come from a variety of academic backgrounds ranging from psychology to history.



Robin Newman, OTD

"We used to have student groups evaluate the utility of an assessment and present it to the class. But that way, they would really learn only about one assessment," Newman says. "When the modules became available, we decided to see if we could give the students a broader understanding of what they can do with assessments."

Recently, Newman asked her students to work through the modules on their own outside of class time. The students then provided feedback to the modules' creators. The feedback has been "overwhelmingly positive," she says. "It really helps them put the pieces together, so they know how to introduce measurement in their clinics when they go out to practice."

Apeksha Gohil, an occupational therapy student at UIC, used the training modules as part of her advanced practicum. Her assignment was to conduct an evidence-based instrument review for inclusion in the Rehabilitation Measures Database. She selected a scale and gathered information about its psychometric properties. With guidance from the modules, Gohil sorted through the literature related to measuring patients' participation in managing their health condition.



Apeksha Gohli

"It's a step-by-step process. I knew I wanted a participation measure because I'm an occupational therapist," she says. Gohil decided to evaluate the Patient Activation Measure, a scale that assesses a person's knowledge, skills, motivation, and confidence about managing his or her own health and health care. She also learned that there are other factors

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RMD's new role (Continued from page 1)

"With these collaborations, we have a very low cost way of adding high quality content," says Moore. "There are a lot of instruments that assess individuals undergoing rehabilitation. We are a long way from having instruments that assess all aspects of rehabilitation in the database."

*"I've had students sign up for the class because of this assignment."
- Stephanie Combs-Miller*

Although the initial database focused primarily on a limited number of conditions and injuries, it has now grown much wider and includes measures that evaluate conditions from Parkinson's disease to multiple sclerosis and low back pain. "We have more comprehensive summaries for more populations," Moore adds.

Stephanie Combs-Miller, PT, PhD, NCS, is one of the professors using instrument summaries as a class assignment. Her graduate-level students at the University of Indianapolis are practicing physical or occupational therapists. Some have used RMD before, while others have never heard of it.



Stephanie Combs-Miller, PhD

"Part of the course objective is to discuss outcome measures and their psychometric properties and to think about how we would use this information for clinical decision-making," Combs-Miller says.

Students choose a measure that hasn't yet been included in the database and then find relevant articles that

have been written about it. Using that information, they fill out a template designed by Moore.

The summaries are peer-reviewed by other students before being critiqued by Combs-Miller and sent back for further revisions. The summaries pass three checks before they are sent to RIC. "We want them to be as clean as possible," she says.

Her students really dig into their task, Combs-Miller says. "They are more motivated by this assignment than others because they know they are contributing to their profession. I've had students sign up for the class because of this assignment."

Charles Sheets, PT, OCS, SCS, Dip MDT, an adjunct instructor in the Doctor of Physical Therapy program at Duke University and the University of North Carolina, is another professor who has incorporated instrument summary writing into his classes.



Charles Sheets, PT

At Duke, students write summaries in a class called "Assessing Outcomes of Care." It is a group project because that is how graduate students in physical therapy are organized for their entire three-year program. Students go online to listen to Sheets' lectures on outcome measures and then come to class to score and interpret them.

Because each student group may have 10 to 12 members, Sheets is looking for measures with enough related peer-reviewed papers to keep them busy. "We've traditionally taken on larger projects," he
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NIDRR Invited Lectureship

We would like to thank David Tulsky, PhD, Director of Assessment, Outcomes and Translational Research, Departments of Orthopaedic Surgery, Medicine, and Rehabilitation Medicine at New York University Langone Medical Center, for being the 2014 lecturer in the NIDRR Invited Lectureship in Outcomes Research series, sponsored by the Rehabilitation Research Training Center on Improving Measurement of Medical Rehabilitation Outcomes. The goal of the lectures is to promote the use of outcome measurement by rehabilitation professionals. Dr. Tulsky lectured at the Department of Physical Medicine's Clinical Grand Rounds at RIC and the **Seminar Series** at the Institute



Linda Ehrlich-Jones, David Tulsky, Allen Heinemann

of Public Health and Medicine at Northwestern University. His presentation, "The State of the Science in Rehabilitation Measurement: Emerging Common Data Elements," can be accessed **on our website**.

Jennifer Piatt (Continued from page 1)

These days, Piatt is an Assistant Professor of Recreation, Park and Tourism Studies at Indiana University in Bloomington, Indiana. About 60 to 70 percent of her time is spent on research, which focuses on increasing social inclusion of individuals with chronic illnesses and disabilities.

Helping teenagers with disabilities engage in sports, such as wheelchair basketball, does much more than just improve their physical condition, she says. “For the majority of their lives, they think ‘I’m the kid with a disability.’ But, we’re finding that when they engage in sports, they start identifying as an athlete. It changes their self-perception,” Piatt says.

In fact, recreational therapy helps patients develop problem-solving skills and encourages new friendships. Some of her patients have gained the confidence to enroll in college, an option they hadn’t considered before.

Such anecdotes are heartwarming, but Piatt wants to make sure that her field has the evidence to back up its therapeutic claims. She acknowledges that recreational therapists are behind their physical and occupational therapist counterparts in creating and using outcome measures. “It all

sounds great, but nobody has really looked at what’s working,” she says. “There’s no broad consensus on how and what to measure. For example, quality of life is a subjective measurement.”

To help remedy that, Piatt is looking

reduce the patients’ symptoms of depression and sense of isolation. “We’ll look at it from a scientific perspective - whether their quality of life improves,” she says.

Piatt also has worked with the Center for Rehabilitation Outcomes Research

The biggest satisfaction is seeing people being able to embrace and live the life they want without limitations.
- Jennifer Piatt, PhD

at specific recreational programs in the Bloomington community and attempting to measure their clinical outcomes. One study with patients who have spinal cord injuries will look at how engaging in sports affects cognition. Brain scans will be used to assess the results.

Piatt also has been brought on as a co-investigator in a small pilot study of 15 senior citizens experiencing clinical depression. The seniors will be provided with Paro, a robotic baby harp seal developed in Japan that responds to touch and sounds.

The study will focus on whether Paro can

(CROR) to develop training modules that are being used to educate therapists and students about measuring outcomes (see related story on page 3).

“She brings a valuable perspective as a recreational therapist and graduate school faculty member. She understands the learning needs of recreational therapists and the educational opportunities and constraints of undergraduate and graduate programs,” says CROR Director Allen Heinemann, PhD. “Jennifer has been an enthusiastic and valued collaborator. She has engaged RIC’s recreational therapists in exploring collaborative research opportunities, too.”



Allen Heinemann, Alex Wong, Jane Holl

Best Wishes to Alex Wong, PhD

Please join us as we bid Alex Wong, PhD, a fond farewell as he finishes a two-year post-doctoral research fellowship at CROR. He leaves to join the Program in Occupational Therapy faculty at Washington University in St. Louis, Missouri. We thank him for his generosity of spirit, enthusiasm, and dedication. We wish you all the best, Alex!

Measurement Modules (Continued from page 3)

that influence a therapist’s choice of a measure such as complexity and cost.

“The modules taught me that I also have to keep clinical utility in mind,” says Gohil, who is working on a clinical doctorate that she plans to finish in December. “They are very practical.”

Gohil says she took away another concept that was even more important. “Even if two patients have the same diagnosis, they are different. That’s what the modules taught me. Each patient is different. That’s what it means to have an evidence-based and patient-centered practice.”

Gohil is building on the knowledge she learned from the modules and is helping Magasi and Allen Heinemann, PhD, who serves as the principal investigator of the grant, co-author a chapter on outcomes measurement for the upcoming revision of the textbook *Measuring Occupational Performance* (Law, Dunn and Baum, editors).

RMD Volunteers

The Center for Rehabilitation Outcomes Research (CROR) staff takes this opportunity to thank our generous volunteers for their hard work developing the **Rehabilitation Measures Database (RMD)**.

Every week, devoted volunteers spend hours adding and editing summaries of rehabilitation outcome measures that have been produced by professional organizations and educational collaborators from around the country. They also complete administrative tasks related to RMD webinars and workshops.

Without their help, we would not have been able to grow RMD to almost 270 instrument summaries this year. With over 80,000 hits a month from over a 100 countries, their work is noticed! Read below to find out what our volunteers do outside of RIC.

Natalie Mordini

Natalie is a senior at the University of Notre Dame, where she is studying Psychology and Applied and Computational Mathematics and Statistics (ACMS). She volunteers with CROR to gain exposure in health services and outcomes research. At Notre Dame, she is a research assistant to a professor and also will work in the Adult Development and Aging Lab beginning in the fall. She will apply to graduate programs in Quantitative Psychology.



Julie Prepura

Julie is taking prerequisite courses to apply for graduate school in Occupational Therapy in Fall 2014 and hopes to work in a hospital to gain more knowledge and experience. One of the highlights of her week is volunteering in the PT/OT clinic at Lurie Children's Outpatient Center in Lincoln Park. It is a small department with supportive and exceptional staff. On the side, Julie babysits and does improvisation at The Second City as well as a three women improv group called TheAfterlaugh.



Rebecca Schuck

Rebecca is a recent graduate of Loyola University Chicago. She volunteers with CROR to gain experience in physical therapy research. In the fall of 2014, she will attend Northwestern University's doctoral program in Physical Therapy and Human Movement Sciences. Aside from research, other clinical physical therapy work includes volunteering in the RIC flagship hospital and working as a Rehabilitation Aide at AthletiCo, an outpatient clinic.



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Articles written by **Susan Chandler**.

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RMD's new role (Continued from page 4)

says. For example, last year students tackled the Lower Extremity Functional Scale, a self-reported measure of lower-leg function that has more than a dozen articles written about it.

As in Combs-Miller's class, Sheets' students fill out a template describing a measure. He also has them find a randomized controlled trial that uses the scale to measure outcomes. The students then write a two- to three-page outline of the study and provide their interpretation of how the tool was used. "Has the tool been validated with those populations? Was the change shown a meaningful change?" Sheets asks. "If you have a large enough population, you can always find a statistical change. But we want the students to understand what a meaningful change is in a clinical setting."

One of the things that his physical therapy students almost always find intimidating is math. "They have very strong math phobias," he admits. To help them get over their fears, Sheets encourages the students, when appropriate, to take the raw data included in a study and put it in a spreadsheet that he developed to perform the necessary calculations. The task reinforces what the students are learning in a statistics class and increases their

comfort with numbers, he says. Doing this also allows for a more comprehensive report.

Sheets is now involved in his third iteration of the project, and he isn't worried about running out of assignments anytime soon. "Measures get developed constantly, and more than likely in a few years, we'll be revising older summaries. Maybe a measure hasn't been updated in 10 years, can we find new literature on it?" he says.

RMD was developed with input from physical, occupational, and speech therapists as well as psychologists and rehabilitation nurses. But therapists tend to focus on highly specific measures of function, while nurses often use more holistic assessments of a patient's progress. So it's not surprising that some measures regularly used by nurses are not yet incorporated in the database. Linda Ehrlich-Jones, PhD, Research Scientist at CROR, asked DePaul University's nursing school to help remedy that limitation.

DePaul integrates instrument writing in a series of three research classes that nursing students are required to complete before receiving their master's degrees. "In the first one, they are thinking about a concept,"

explains DePaul Associate Professor Matthew Sorenson, PhD. "For example, how people define stress depends on their philosophical and theoretical underpinnings. Some measure it as an accumulation of life dynamics. Some measure it as a psycho-cognitive state."

In the second class, students write a research proposal to evaluate an outcome measurement that is used in nursing, but hasn't been examined from a nursing perspective.

"For students who aren't interested in designing their own project, but are interested in something with direct clinical applicability, this works well because they are contributing to a database that is used by a lot of people," Sorenson says.

In the third class, students finish writing their instrument summary and present a poster about it at the school's research day. They're expected to explain their work to fellow students, as well as administrators. "That's what we're expecting to see in terms of scholarship - the ability to present effectively in a professional setting," Sorenson says. "You may have a fantastic project but unless you can share it, no one will ever know."

If you are an educator and interested in collaborating or writing instrument summaries for RMD, please contact, Jason Raad at jraad@ric.org



Matthew Sorenson, PhD

RIC Quality Fest

Kudos to CROR Project Coordinator Arielle Goldsmith for leading a quality improvement initiative entitled "Improving Research Staff Knowledge when Working with Individuals



Ana Miskovic, Dr. Allen Heinemann, Arielle Goldsmith

Living with A Disability." Each year, RIC hosts Quality Fest, an organization-wide competition that allows employees to identify areas in need of improvement, create solutions for the problem, and assess the effectiveness of the intervention.

As a result of the CROR

team efforts, RIC is presenting a series of brown bag seminars to address patient safety and care concerns for researchers.

The first seminar, Working with Individuals with a Disability, was scheduled on July 21, when Dr. Kathleen Stevens, Director of Nursing Education, focused on identifying and managing symptoms and co-morbidities that may occur with individuals living with a disability.

We also thank Ana Miskovic for leading data analysis and Jessica Presperin-Pedersen, Sara Jerousek, and Holly Neumann for their helpful insights.



Kathleen Stevens, PhD