



Rehabilitation Institute of Chicago  
Center for Rehabilitation Outcomes Research

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# CROR Outcomes

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## Fixing the Assessment Gaps in Rehabilitation: RIC's Novel Approach



James Sliwa, DO

Rehabilitation encompasses a wide variety of disciplines, including physiatry, physical therapy, occupational therapy, speech language pathology, psychology and more. Each field has its own scales and tests to measure how a patient benefits from treatment.

However, according to James Sliwa, DO, Senior Vice President of Medical Affairs & Chief Medical Officer at the Rehabilitation Institute of Chicago (RIC), there has not been a comprehensive,

but simple, instrument to assess outcomes of individuals typically served by inpatient rehabilitation facilities.

For instance, patients are not consistently assessed in areas relevant to their diagnosis. Typically they are assessed with tools lacking the necessary sensitivity and refinement to measure real progress, and must undergo a gauntlet of sometimes overlapping assessments that can take many hours. Sliwa and his colleagues have launched a program to address the gaps and shortcomings in the current approach to assessing outcomes.

The vision? To develop a tool that is more sensitive and comprehensive in assessing outcomes while decreasing assessment burden.

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## Report from Canadian Conference: RRTC Researchers Reducing Barriers to Measuring Outcomes

Outcome measures for patients with neurological impairments are hampered by barriers and disparities in measurement, a team of U.S. researchers reported at a symposium during the International Society for Quality of Life Research in Vancouver, British Columbia in October 2015.

Allen Heinemann, PhD, Director of RIC's Center for Rehabilitation Outcomes Research and Professor in Physical Medicine and Rehabilitation and Medical Social Sciences at Northwestern University Feinberg School of Medicine, says using a sample of 604 patients with three impairments (stroke = 211; spinal cord injury = 209 and traumatic brain injury = 184), researchers explored these topics:

1. Computer-based measurement of health literacy, functional literacy, cognitive function and patient-reported outcomes;
2. Measuring economic quality of life;
3. Modeling social outcomes with cognitive and environmental measures;
4. Impact of reasonable accommodations on validity of cognition measures among people with neurological impairments;
5. Emotional functioning and quality of life.

The symposium draws on data collected as part of the Rehabilitation Research and Training Center funded by the National Institute on Disability, Independent Living, and Rehabilitation Research. The research was supported over

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## CROR Outcomes: Winter 2016



Welcome to Winter at the Center for Rehabilitation Outcomes Research. This issue features a cover story on the development of a novel approach to functional outcomes measurement at the Rehabilitation Institute of Chicago (RIC). Our staff and collaborators share new knowledge on outcomes in patients with neurological impairments that we shared from the International Society for Quality of Life Research symposium in Vancouver, British Columbia.

On page 3 we focus our collaborator profile on Dr. Chih-Hung Chang, Director of Clinical Outcomes and Informatics at RIC and Professor of Physical Medicine and Rehabilitation at Northwestern University Feinberg School of Medicine. Our staff profile introduces Kelsy Stipp, Research Assistant at CROR, conducting outcomes research on people with spinal cord injuries.

Finally, we recognize our new CROR volunteer, Barbara Rodichok, who is assisting with the development of instrument summaries for patients with stroke and cancer in the RMD.

For more information about our projects and educational opportunities, please visit our webpage at [www.ric.org/cror](http://www.ric.org/cror). And don't forget to "like" us on Facebook!

Allen Heinemann, Director

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# CROR Outcomes

The Center for Rehabilitation Outcomes Research (CROR) conducts studies measuring how medical rehabilitation and health policies impact people with disabilities. The Center also examines methods to increase effectiveness and efficiency of the rehabilitation process. CROR is a part of the Rehabilitation Institute of Chicago – ranked #1 Rehabilitation Hospital for 24 Consecutive years by U.S. News & World Report.



Center for  
Rehabilitation  
Outcomes Research

## CROR Research Assistant Has Her Eye on Becoming a Clinician



Kelsey Stipp, MS

Kelsey Stipp, a research assistant at the Center for Rehabilitation Outcomes Research (CROR) since October 2014, has been involved with scientific research since graduate school in anatomical sciences and neurobiology and

psychology at the University of Louisville.

For her master's thesis, she studied depression and anxiety in rats with induced spinal cord injuries. "Yes, rats can be depressed," notes Stipp.

She says healthy rats ran around and explored their environment, while depressed rats would cower in a corner.

She's happy to be done with rodent research and now involved in research at CROR on humans with spinal cord injuries.

Stipp conducts follow-up interviews with patients enrolled in the Midwest Regional Spinal Cord Injury Model System Database, part of the National Spinal Cord Injury Database. The interviews occur close to the one-year anniversary of the injury date with follow-ups at five-year anniversaries after that.

Stipp says the telephone interviews take about a half hour. "We see how people's activities of daily living are going once they leave RIC. We also see if there are any health issues once they leave RIC," she says. "We're seeing a lot of interesting things with aging and spinal cord injury because more people are living a longer time."

The oldest person she has interviewed is 96, and the youngest is 6. "They actually enjoy sharing their insights and helping in any way that they can," she says.

Allison Todd, project coordinator, says the data are used to investigate the relationships between a variety of factors. Identifying and comprehending these relationships could improve patient care or therapy or suggest directions for future research.

Todd says Stipp has a nice way with the research subjects. "A lot of patients say she is charming; she's nice; she's thorough and professional, at no point does she make you feel that you're under a microscope."

She has enjoyed her move to Chicago, but has found the weather a bit strange. "The first time I saw the lake freeze over I was so confused. I didn't expect it to freeze," she said. She'd prefer it if the city had more hot weather.

Stipp wants to travel. She just toured Italy,



including Florence and Rome. And she reads a lot. Nine months into 2015, she reached her goal of reading 100 books, mainly novels. Recently, she read "Loving Day," a novel by Mat Johnson about overturning the ban on interracial marriage in the U.S.

Stipp says her experience at RIC is pointing her towards a career as a clinician. She wants to return to graduate school to earn a doctorate in clinical psychology.

She isn't sure of a specific direction, though she is considering focusing on patients with brain injuries or more generally with patients with anxiety and depression.

"I would prefer to be a clinician and actually sit down and talk one-on-one with people," Stipp says.

## CROR's New Volunteer Barbra Rodichok

CROR welcomes its newest volunteer, Barbra Rodichok, who is a second-year doctor of physical therapy student at the University of Illinois at Chicago. Prior to becoming a full-time graduate student, Barbra had an 11-year career in search engine optimization and web project management, including four years with Northwestern University. She is looking forward to beginning her clinical internships so that she can put together everything she's learned over the past two years. Ultimately, she hopes to combine her career experiences in two distinct fields to bridge research findings with clinical practice, and improve patient outcomes. Working with the CROR team is a fantastic opportunity to do just that! When she's not studying, Barbra enjoys listening to science podcasts and flamenco dancing, but not at the same time.

CROR appreciates Barbra for all of her hard work to ensure that the RMD continues to grow. Barbra is helping to organize and collect literature so that the Cancer and Stroke EDGE groups with the American Physical Therapy Association can add and expand new measures into the RMD. Thank you, Barbra!



Barbara Rodichok

## Report from Canadian Conference: RRTC Researchers Reducing Barriers to Measuring Outcomes (Continued from page 5)

tive function by examining the ability of people with neurological impairments to complete the NIH Toolbox Cognition Battery.

They found that most people with neurological impairments can complete the testing with accommodations, but even a significant number (63 patients or 8.6 percent) faced major difficulties even with accommodations.

"It is critical that test administrators understand the effects of accommodations on scores and that interpretations be informed by actual practices. At a more fundamental level, test developers should consider accessibility at the design, administration and interpretation stages," Magasi says. "The bottom line is that people make a lot of assumptions on what accommodated versions of tests mean for interpretability of derived scores but the issue has rarely been studied empirically. We are advocating for rigorous evaluation of the impact that accommodations have on scores."

—Building an economic quality of life (ECQ) scale.

David Tulskey, PhD, University of Delaware, Newark, says that research has demonstrated that individuals with lower socioeconomic status have poorer health outcomes, but the effects on quality of life (QOL) from disparities remains understudied. "Individuals with disabilities often have fewer resources because of unemployment, poorer health status, and greater health care needs," he says.

He described the process of constructing and field testing an ECQ scale on individuals with impairments living in the community.

"The economic quality of life (ECQ) scale defines a unique construct for which there is no other measure," he says. "Its development addresses an issue highly salient to individuals with disabilities. The ECQ scale allows investigators to address economic and disability-related health disparities."

—Examining health literacy in patients with neurological impairments.

Elizabeth Hahn, MS, of Northwestern University Feinberg School of Medicine

in Chicago, says all people require health literacy to navigate the health care system and function in their daily lives. People may be unfamiliar with the vocabulary used in the health care system.

"Limited health literacy is widespread and is associated with poorer health care access and outcomes; it may also be associated with poorer cognitive abilities," she says.

She undertook a study to measure health literacy and cognition in a medical rehabilitation sample.

Hahn reports that most study participants did not need assistance in operating computer equipment. Thirty-eight percent preferred a touchscreen plus an audio device while 37 percent preferred text only and 25 percent had no preference in completing measures of patient-reported outcomes.

Participants in the stroke group reported the poorest overall health (37 percent poor/fair) compared to those with a spinal cord injury (17 percent poor/fair) or traumatic brain injury (19 percent).

## RMD Instrument Summaries Updates

We are excited to continue our educational collaboration for Winter 2016 with Heidi Fischer, MS, Clinical Assistant Professor at the University of Illinois at Chicago Department of Occupational Therapy. We have changed gears with this dually beneficial collaboration between the Rehabilitation Measures Database (RMD) and Occupational Therapy students. Instead of writing new instrument summaries, Heidi's students are editing over 20 existing summaries in the RMD that have not been reviewed for the past 2-3 years. Heidi's students will conduct thorough literature searches for new articles that have been published since the measures were entered into the RMD. We appreciate their hard work as they balance a challenging project with their intense academic work load.

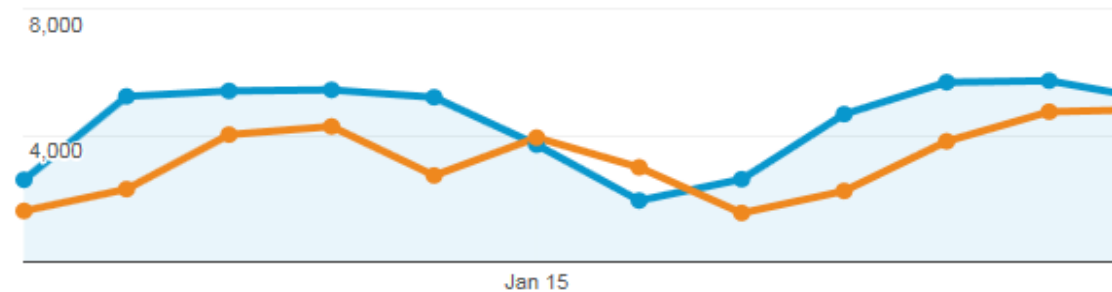
These relationships allow students to have an informal publication on the RMD website, along with an opportunity for a citable publication in one of several rehabilitation journals that has teamed with the RMD.

Don't miss out on an opportunity to be an integral part of the RMD database, which receives over 140,000 monthly hits and is the home of more than 330 instrument summaries. For more information, contact the RMD Project Coordinator, Jill Smiley, at [jsmiley@ric.org](mailto:jsmiley@ric.org).

## RMD Website Traffic

Jan 10, 2016 - Feb 9, 2016: ● Sessions

Jan 10, 2015 - Feb 9, 2015: ● Sessions



Sessions

**31.14%**

143,094 vs 109,113

Users

**27.83%**

97,338 vs 76,147

Pageviews

**29.43%**

305,594 vs 236,110

## Acknowledgements

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organizations for their continued support. Articles in this issue written by **Howard Wolinsky**.

**Note:** The contents of this newsletter does not necessarily represent the policy of the Department of Health and Human Services, and you should not assume endorsement by the Federal Government.

## Subscriptions and Archives

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Visit <http://www.ric.org/cror> and click on "Newsletters." Print versions of past issues are also available upon request.

## Dr. Chih-Hung Chang: Finding the Right Questions

Dr. Chih-Hung Chang, Director of Clinical Outcomes and Infometrics at the Rehabilitation Institute of Chicago (RIC) and Professor of Physical Medicine and Rehabilitation at Northwestern University Feinberg School of Medicine, started exploring his career during his college years in his native Taiwan as a volunteer counselor helping teens adjust to the demands of home and school.

But he discovered in his heart he was a numbers man who wanted to use math and computers to create methods to measure psychological factors to help clinicians understand and treat patients.

"Basically, I started out people oriented. Now I am more numbers or computational methods oriented. Two very different things," he says.

Chang transformed himself from a college psychology major in Taiwan in the 1980s to an international leader in measuring psychosocial factors affecting cancer patients and now patients undergoing rehabilitation for stroke, spinal cord injuries, brain injuries and other conditions.

He came to Chicago in 1988 because the University of Chicago offered him a full scholarship and because it is a leader in quantitative psychology or psychometrics, the branch of psychology concerned with the design and use of psychological tests and the application of statistical and mathematical techniques to psychological testing. He received training from Professors R. Darell Bock, Benjamin D. Wright and Robert D. Gibbons, and received his Ph.D. in 1995.

Initially, Chang joined Rush University Medical Center, where he became involved with the early research quantifying

the quality of life in cancer patients. He says psychosocial factors traditionally had been overlooked in these patients. "Doctors often focused on treating physical symptoms in cancer patients," he says. He helped develop assessment tools for use in diverse cancer patient populations and patients with chronic illnesses utilizing item response theory (IRT).

He then focused on elderly cancer patients receiving palliative and end of life care as well as patients with Alzheimer's Disease and related disorders and their family caregivers while working at the Buehler Center on Aging, Health & Society of Northwestern University's Feinberg School of Medicine.

His research on developing psychometrically sound and clinically relevant assessment tools caught the attention of the leadership at RIC. He was recruited to work on an initiative at RIC to develop a new system to assess functional outcomes. (See accompanying article.)

James Sliwa, D.O., Chief Medical Officer at RIC, says there are many instruments already in existence. But he notes there is



Chih-Hun Chang, PhD

Chang showed the reporter a list of more than 30 instruments he is studying that would require more than 40 hours to conduct in the rehabilitation patient population.

Clinicians are collecting data and Chang is performing psychometric evaluations to reduce the number of items in testing, making them more manageable for patients and clinicians.

Chang wants the assessment to take less than an hour: "That's my goal. I just wanted to basically ask a couple questions in terms of your current ability level as well as where you want to be able to be after you've been discharged from the hospital. So there is a goal as well with your

*"I just wanted to basically ask a couple questions in terms of your current ability level as well as where you want to be able to be after you've been discharged from the hospital."*

Chih-Hung Chang, PhD

a need to reduce the assessment burden the amount of time and effort needed to assess rehabilitation patients.

He says: "Dr. Chang is the person to take that information, look at those items and see if indeed there are items on a test that overlap or we don't need."

current condition. So we try to match the goal as closely as possible."

Chang and Sliwa agreed that the search for this assessment will take years.

"We have to find the right questions," he says.

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## Fixing the Assessment Gaps in Rehabilitation: RIC's Novel Approach (Continued from page 1)

In the summer of 2014, Joanne C. Smith, MD, President and CEO of RIC, charged a "SWAT team" of RIC executives, scientists and clinical leaders to develop an assessment system that demonstrates to payors, such as Medicare, that the services RIC and other inpatient rehabilitation hospitals provide are beneficial in meeting patient needs.

Supported by Sliwa, the SWAT team includes Peggy Kirk, Senior Vice President & Chief Clinical Operating Officer, Nancy E. Paridy, JD, Senior Vice President, General Counsel & Government Affairs, and Betsy Owens, Senior Vice President & Chief Marketing & Innovation Officer. The clinical team is made up of master clinicians throughout the RIC continuum and is led by practice leaders from Staff Development. To date, clinicians have logged dozens of hours on the project.

"For patients undergoing rehabilitation, a system to assess outcomes should include not only the patient's ability to bathe, dress and groom, but also areas of patient improvement not presently reported," explains Allen Heinemann, PhD, Director of the Center for Rehabilitation Outcomes Research. "Dr. Smith contends that the generic across-the-board indicators currently in use can be helpful, but don't fully demonstrate the gains achieved by patients at RIC and other inpatient rehabilitation hospitals."

The SWAT team meets frequently to ensure steady progress against a defined process that integrates diverse clinical insights and statistical analysis to cull the most sensitive and reliable indicators. "The group has identified a set of standardized assessments, evaluated their utility and now is narrowing and winnowing these tools," Heinemann adds.

Chih-Hung Chang, PhD, Director, Clinical Outcomes and Infometrics at RIC, is a quantitative psychologist who previously worked on tools to assess patients with cancer. He has been working on refining outcomes assessment in patients undergoing rehabilitation. (See accompanying

profile.) "Dr. Chang is extracting data from our set of standardized assessments and doing statistical analysis to evaluate if there is redundancy in those standardized assessments," says Heinemann. "For example, there are balance tests that require patients to balance standing on one foot, standing on both feet and then maintaining balance while being pushed. Those tests take a lot of time to complete, and Dr. Chang's analysis, along with clinical input, is helping to identify the most relevant and nonredundant items that illustrate meaningful patient progress."

Sliwa points to early progress. "Dr. Chang looks for items that overlap, and that we don't need. For example, we have already illustrated that if you take a certain assessment tool with 14 items, we can eliminate six of those without compromising the sensitivity of the tool."

Chang has worked closely with clinicians to understand what they want to measure. "We want to create a comprehensive tool that can be used for any type of condition," says Chang. "The SWAT team has identified, from existing tools, ways to assess mobility, physical function and cognitive ability. In the future, new technologies will allow the patients, the clinicians and researchers to see the data being collected in a real-time fashion."

Data will be collected prior to, during and after patients visit clinicians. A computer will synthesize the data on an ongoing basis, allowing clinicians to discuss how patients are faring and what can be done to improve their conditions.

*"...we have already illustrated that if you take a certain assessment tool with 14 items, we can eliminate six of those without compromising the sensitivity of the tool."*

—James Sliwa, DO

"In the end," says Chang, "I want to be able to ask a limited set of questions and pretty much know where the patients are in terms of current ability level, as well as where they want to be after they've been discharged from the hospital." Sliwa says the collaboration between Chang and clinicians illustrates what is envisioned for RIC's new research hospital, opening in 2017. "The

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## Fixing the Assessment Gaps in Rehabilitation: RIC's Novel Approach (Continued from page 4)

big picture is to embed researchers and clinicians together, in the same space. This model will improve translation of research findings into clinical care and

also bring those individuals together to stimulate conversation. Researchers will better understand clinical ramifications and what's important to patients. Clini-

cians, for their part, will participate in research to help develop meaningful research projects that translate into better outcomes for patients."

## Report from Canadian Conference: RRTC Researchers Reducing Barriers to Measuring Outcomes (Continued from page 1)

five years with a total of \$4.2 million in grants. Patients in the sample came from Chicago, St. Louis and Ann Arbor, Mich.

Lead researchers reported on the following topics in Canada:

—Testing models of social outcomes in patients with neurological impairments to investigate the complex relationships between cognitive, emotional, physical, environmental factors and participation in social and community activities.

"Unfortunately, there is no gold standard for the measurement of social health outcomes, which are multifaceted, complex and individualized. Furthermore, participation in social or community activities can be influenced by multiple factors including opportunities, environmental barriers, social roles, and various aspects of body function," says Alex W. K. Wong, PhD, DPhil, Program in Occupational Therapy and Department of Neurology, Washington University School of Medicine, and a former postdoctoral fellow at RIC.

Wong says the study found that barriers in the built environment, limited access to information and technology, poorer social environment and limited health

and community services, were significantly associated with lower levels of participation in social roles, participation enfranchisement, and economic quality of life.

"These findings can provide guidance for interventions and policy initiatives targeting environmental barriers," he says.

—Health disparities relating to health-related quality of life (HRQOL) for individuals with neurological impairments.

Noelle Carozzi, PhD, University of Michigan, Ann Arbor, and colleagues examined 17 patient-reported outcome measures across four subdomains of emotion: Psychological Well-Being, Social Relationships, Stress and Self-Efficacy, and Negative Affect. Demographic group comparisons were conducted for gender, education, race, ethnicity and socioeconomic status.

"Those with greater income ... reported less personal rejection, less anger and more general life satisfaction than those with lower income. While results suggest some health disparities in HRQOL for race, they especially highlight health disparities for socioeconomic status," says Carozzi. "While the findings suggest that environmental factors may have

some influence on self-reported emotion, these relationships are very small. Future work is needed to understand better such disparities so that interventions might be developed to mitigate such effects."

—Need for accommodation in outcome measures.

Susan Magasi, PhD, University of Illinois at Chicago, and Mark Harnis, PhD, University of Washington, looked at barriers affecting human-computer



Susan Magasi, PhD

interactions in computer administered, performance-based measures of cogni-

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