

State of the Science

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Dr. Greg Worsowicz

His career in rehabilitation medicine and collaboration on CROR research projects on *Page 2*.

CROR Dissemination

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Summer 2012: Research Priorities for Rehabilitation



Thank you for joining us for the Summer 2012 issue of **CROR Outcomes!** In this edition, we check in with one of the research projects in our Rehabilitation Research and Training Center (RRTC) on Improving Measurement of Medical Rehabilitation Outcomes. We give an update on data collection efforts and the

study's progress in validating cognition measures. In addition to quotes from our hard-working staff and collaborators, you can read about data collection from the perspective of the study participant.

Inside are profiles on two physiatrists with whom we are proud to collaborate. First, the spotlight is on a local physician, Dr. Elliot Roth, in an article about his work in stroke research at RIC. Next, we profile

an Advisory Committee member from the University of Missouri School of Medicine, Dr. Gregory Worsowicz. Read about his career in rehabilitation on page 2.

We also give a report on our State-of-the-Science Conference on Outcome Measurement in Medical Rehabilitation, held March 5-6 in Arlington, VA. We gathered top researchers, educators, policy makers, clinicians and consumer representatives to discuss the need for improved measurement in rehabilitation. Read about conference proceedings and recommendations for future research priorities on page 3.

Lastly, read about updates to our Rehabilitation Measures Database on page 6, including an exciting webinar opportunity.

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

Dr. Elliot Roth: RIC Physiatrist and Stroke Researcher

Elliot Roth was planning a career in family medicine or pediatrics when he spent the summer after his first year of medical school shadowing physicians at the Rehabilitation Institute of Chicago in a medical student externship program.

As he watched doctors working with patients dealing with serious disabilities, Roth realized that rehabilitation work was both personally satisfying as well as intellectually challenging.

"I needed to understand that patient problems had a basis in basic science, but also had significant personal meaning for them," says Roth, MD, Chairman of the Department of Physical Medicine and Rehabilitation at Northwestern University's Feinberg School of Medicine and Medical Director of the new Patient Recovery Unit at the Rehabilitation Institute of Chicago (RIC).

"It's about helping people open a cabinet door but also understanding what muscles

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Project Update: Data Collection for Validation of Cognition Measures

It's an ambitious undertaking—putting 600 patients in three cities through a two-day battery of tests to assess everything from their emotional well-being to their level of community participation.

But that's the task undertaken by the Rehabilitation Research and Training Center on Improving Measurement of Medical Rehabilitation Outcomes. The goal is to better assess

As the testing has progressed, the researchers have learned from their subjects and adapted their procedures.

the recovery process for people with traumatic brain injuries, spinal cord injuries and stroke and, in the longer-term, improve the quality of their lives.

"The testing is going relatively smoothly," says Sara Je-

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Dr. Gregory Worsowicz



Gregory Worsowicz is sure that some doctors get satisfaction from seeing their patient's blood pressure drop 20 points or getting a bad case of heartburn under control. But he finds it hard to believe that feeling can compare with the reward he gets from helping paralyzed patients regain a function they feared was lost forever.

"If I'm tetraplegic and you can help me grab a cup and sip by myself, I love you," says Worsowicz, MD, Chairman of the Physical Medicine and Rehabilitation Department at the University of Missouri School of Medicine in Columbia, Mo. "We all love to be independent. We all love to do things on our own."

Worsowicz has never regretted his choice to specialize in rehabilitation even though the field was just a niche when he was a medical student at the University of Florida in the mid-1980s. His career took him to Texas for a residency at Baylor College of Medicine in Houston, then to a combination of teaching and private practice in New Jersey before he was recruited to Mizzou in 2002. In addition to his academic position, Worsowicz chairs the physicians' group at the university, which includes almost 500 practitioners.

of CROR.

"He made a number of astute observations and suggestions. He also took the time to prepare a presentation, which he didn't have to do."

Heinemann adds: "He is very unassuming and devoid of pretension but that casual style conceals his intellect and his appreciation of healthcare delivery locally and nationally."

Worsowicz sees his role on the committee as a voice for physicians who must deal with numerous everyday problems and the irritations of running a practice. "I'm not a heavy researcher. I'm a practical person as far as seeing patients, running a practice plan and dealing with insurance companies. I'm kind of an acid test. I ask questions like 'How much time does it take?' and 'How does it help my patients?'"

One area that interests Worsowicz is how the internet and electronic medical records can improve communication between patients and physicians.

Many people now prefer making appointments online rather than waiting on hold with a doctor's office, he notes. A growing number prefer to get their test results through a secure website. And some are asking for text messages to remind them of their upcoming appointments.

"Our practice and technology needs to change," he says.

The reward for physicians who stay on the cutting edge of technology is clear, Worsowicz adds. "Patients don't know if I'm any good or not. They expect I'm good, but people think highly of physicians who communicate well. No matter where you're practicing medicine or what type, it's all about service."

"...People think highly of physicians who communicate well. No matter where you're practicing medicine or what type, it's all about service."

Dr. Gregory Worsowicz

He brings all of that expertise to the Center for Rehabilitation Outcomes Research (CROR), where he serves as a member of the advisory committee for the Rehabilitation Research Training Center on Improving Measurement of Medical Rehabilitation Outcomes.

"He contributes his time freely. He attends meetings, reviews and also comments on documents. And he attended our State of the Science conference last March," says Allen Heinemann, Ph.D., Director

Fellow Recognition

At RIC's annual fellows' recognition reception on April 11, 2012, **Lucy Bilaver, Allan Kozlowski, Megan Morris** (pictured, left to right, with **Dr. Allen Heinemann**) received recognition for their scholarly activities.

Dr. Kozlowski, working in the Center for Rehabilitation Outcomes Research, will finish his internship this fall. Dr. Bilaver, who completed her fellowship this summer, has taken a faculty position at Northern Illinois University and will continue working at Chapin Hall at the University of Chicago. Congratulations!



State-of-the-Science Conference on Outcome Measurement in Medical Rehabilitation

Making breakthroughs in rehabilitation research is one thing. Translating those findings to clinicians in the field who actually work with patients is another. How to communicate knowledge more quickly and efficiently was one of the themes of a recent conference outside Washington D.C. focused on the State of the Science of Outcome Measurement in Medical Rehabilitation.

The conference was hosted by Allen Heinemann, Ph.D., Director of the Center for Rehabilitation Outcomes Research (CROR) at the Rehabilitation Institute of Chicago (RIC). The purpose of the conference was to bring together experts in the field to discuss recent progress in rehabilitation outcome measurement and to prioritize recommendations for future research. The grant funder, the National Institute on Disability and Rehabilitation Research (NIDRR), requires RRTC recipients to hold such a conference in order to track developments and target future areas for government-funded research.

More than a dozen top researchers, educators, policy makers, consumer and professional organization representatives, and clinicians attended the two-day event in Arlington, Virginia, in early March. “We invited both collaborators and others whose work we know and respect,” said Heinemann. “Everybody we invited accepted. We held planning meetings in advance to assure that presenters would cover the field’s needs in a comprehensive manner.”

Among the attendees were Charlie Lakin, Ph.D. Director of NIDRR. NIDRR is committed to funding research that helps improve the lives of people with disabilities.

All of the conference participants agreed on one thing, Heinemann said: “The need for improved measurement is so broad and diverse and the funding limits so severe, we have to prioritize because we will never get through the whole agenda.”



State of the Science Participants at the Ritz-Carlton in Arlington, VA

Added Jillian Bateman, clinical research coordinator at CROR and organizer of the conference: “There were a lot of very knowledgeable people around the table. It was very exciting to be part of something that could have a large impact on future research agendas.”

The conference was organized around several themes including the need to improve measurement of cognition, environmental fac-

tors and community participation. Also on the agenda was the use of common data elements in research and assuring that assessment procedures be accessible to people with disabilities.

Although there is much research going on in the medical rehabilitation field, researchers cannot accurately compare findings across studies and aggregate that information unless they use a common set of data elements. David Tulsy, Ph.D., Director of Research in the Department of Physical Medicine and Rehabilitation at the University of Michigan, noted that there is still a disconnection between researchers who prefer “legacy” instruments and those who favor new instruments with psychometric components that account for variables such as intelligence and personality traits.



Dr. Tulsy Presents

He pointed to several common data elements relevant to rehabilitation, including the National Institutes of Health Toolbox for the Assessment of Neurological and Behavioral Function and other instruments that measure quality of life for those with neurological disorders and spinal cord injuries. But obstacles remain for their adoption, Tulsy said, including a lack of awareness about the progress being made by investigators.

On another topic, Gale Whiteneck, Ph.D., Director of Research at Craig Hospital in Colorado, discussed the challenges of measuring levels of community participation by people with disabilities. Part of the challenge comes from blurred distinction between a person’s performance in social roles and the amount of outside activities they engage in. Social role performance—which measures a person’s productivity, self-perception and self-worth—may be significantly different and better than their ability to be active and participate in their community, he noted.

The fact that people have the chance to choose those activities they participate in dramatically complicates attempts to measure community participation, Whiteneck said. For now, given the lack of reliable measures, he urged researchers to keep separate the concepts of objective participation performance and subjective satisfaction with that participation.

There are also shortcomings in the field of measuring cognition in disability samples, said Noelle Carlozzi, Ph.D., Assistant Professor at the Center for Rehabilitation Outcomes and Assessment Research at the University of Michigan. Even though some neuropsychological tests have been standardized and validated, results can be biased because of age, education and culture or an emphasis on psychiatric functioning, she said. There also is limited information about test validity for rehabilitation populations.

One group where the shortcomings of cognitive evaluation are particularly evident is those with spinal cord injuries, Carlozzi said. Because of the severity of their physical limitations, patients’ mental

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Dr. Elliot Roth (Continued from page 1)



you use to do that. It's also about the frustration that comes when you can't do that."

Roth has spent his entire medical career at Northwestern, starting as a medical student and physical medicine and rehabilitation resident, and then becoming RIC's first post-resident fellow in 1986 where he did patient research and learned specialized training in stroke care. Later, he joined the medical staff at RIC and became a faculty member at Feinberg.

Roth started in spinal cord injury care and then went on to found the Center for Stroke Rehabilitation at RIC and spent the next four years focused on patient care, research and teaching. He also obtained a five-year Rehabilitation Research and Training Center grant focused on stroke rehabilitation from the National Institute on Disability and Rehabilitation Research (NIDRR) that has since been renewed four times.

In 1994, he became RIC's medical director while he was chairing the physical medicine department at Feinberg. Although he continues as department chair at the medical school, he is no longer the medical director of the Institute, using the time to expand his inpatient and outpatient practice, and his research portfolio. "I love seeing patients," Roth says, "and I also love doing research." Presently, he directs two large grants from NIDRR, the Stroke Rehabilitation and Training Center, and the Midwest Regional Traumatic Brain Injury Model System Center.

He also works closely with the Center for Rehabilitation Outcomes Research (CROR), says Allen Heinemann, Ph.D., and CROR's director. "He is our bridge to Northwestern University and the medical school. He is a marvelous collaborator."

In his 25+-year career, Roth has seen many rehabilitation practices improve and evolve. One thing that has changed is the intensity of therapy for stroke survivors, especially early in their recovery process. Using treadmills with harnesses to support partially

paralyzed people and help them walk in a more normal gait pattern is just one example and is the subject of a current study at RIC.

"There's much more attention to intensive activation and mobilization," Roth says. "So many problems of stroke relate to immobilization, passivity and inactivity."

One thing hasn't changed nearly enough, though—the small portion of stroke patients who return to work. Statistics show that one-third of people with stroke return to work while the rest remain unemployed. "I think that's pretty small," Roth says.

He says there are probably many reasons. Some patients and family members may fear that the stress of work could cause another stroke. Or it could be that many physicians and employers don't really understand that it's a realistic option.

"Many employers aren't opposed—they just don't know it's possible. Or they think accommodations are going to be expensive," Roth says. "But the bigger issue is attitudinal. There may be co-workers who think, 'This is not attractive. We don't want this.' What we've found is that one thing that drives people's satisfaction is the openness of their immediate supervisor—the person's boss."

When Roth looks at the state of outcomes measurement in the rehabilitation field, he sees progress but not enough.

"We've set the ground work and are ready to go into the middle stage. It's all about objective, standardized and quantitative measure," Roth says. "Many measures in rehabilitation until now have been squishy—qualitative, anecdotal and moderately subjective. The more we can standardize, the more we can help the field and ultimately, patients."

Acknowledgements

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Articles written by **Susan Chandler**.

Note: The contents of this newsletter do not necessarily represent the policy of the Department of Education, and you should not assume endorsement by the Federal Government.

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Validation of Cognition Measures (Continued from page one)

rousek, the project manager who is overseeing the effort. The Rehabilitation Institute of Chicago (RIC), which is handling the Chicago portion of the testing, already has completed almost 100 cases.

The two other research centers—Washington University in St. Louis and the University of Michigan in Ann Arbor—began recruitment several months after RIC. But now that their staffing is in place, they should catch up with RIC by the end of the year, Jerousek predicts.

David Tulsky, Ph.D. an expert on patient-reported outcome measures, is the principal investigator and oversees data collection in Michigan. Carolyn Baum, Ph.D., a leading researcher in independent living for older adults, is heading up the project in St. Louis. And, Allen Heinemann, Ph.D., Director of the Center for Rehabilitation Outcomes Research (CROR) at RIC and Director of the Research and Training Center, is overseeing the project in Chicago.

The study is using the National Institutes of Health Toolbox for Assessment of Neurological and Behavioral Function which is designed to standardize outcome assessment in the areas of neurological function and behavioral health. The toolbox includes tests for motor, cognitive, sensory and emotional functioning. Research subjects also complete questionnaires about community participation and environmental factors that affect participation.

The goal is to complete data collection and analysis by August, 2013.

Key to the project's success is recruiting former patients who are willing to go through several days of testing. So far that hasn't been a problem. "People have been receptive. I'm not sure they really know what they're getting into but by the end, most of them have had a good time," Jerousek says.



Data Collectors Sara Jerousek and Arielle Goldsmith prepare a peg board for Day 2 of testing

Joyce Armour is one of the participants. She sustained a stroke two years ago and uses a leg brace to walk. The 45-year-old former journalist found the testing process "very long, but very informative."

"I believe it was a two-way street. It gave me a sense of what they were looking for in terms of my recovery process."

The tests typically take about six hours, but some patients have completed them in as little as three hours. Others have needed eight hours.

"There's a lot of mental fatigue especially after the first day, but people say they enjoy the challenge," says Arielle Goldsmith, a research assistant at CROR who works directly with former patients

The study is using the NIH Toolbox for Assessment of Neurological and Behavioral Function, which includes tests for motor, cognitive, sensory and emotional functioning. Research subjects also complete questionnaires about community participation and environmental factors that affect participation.

being tested. "It makes them realize skills where they can improve and also activities they are good at, and activities in which they excel."

The first day of testing kicks off with two rounds of neuropsychological assessment, including a battery of memory tests. The tests are administered on paper and by computer to see if the results are consistent. "We're using both modalities to test their reliability and see if we get the same information from the computer test as from the paper test, which has been around for years," Jerousek says. Participants then move on to a community survey about mobility and the day ends with a quality of life survey about communication, self-reported cognition and social support.

Day two is focused on motor skills testing. Participants complete a grip-strength test and are asked to balance on a level surface and a flexible surface with their eyes both open and closed. There's also a four-meter walking test and a distance test that measures how far subjects can navigate in a two-minute time period. Sensory tests that evaluate smell, taste, vision and hearing also are on the agenda, as are more questionnaires about emotional well-being and quality of life.

Goldsmith has been impressed by the determination of some subjects, particularly when it comes to physical tasks and mental challenges. "A lot of their performance has to do with personal motivation. Some people are willing to push themselves above and beyond. There are other people who say, 'There's no way I can do this.'"

Working with people face-to-face has been particularly rewarding, she adds. "You can speak with someone on the phone but when you work with them for an extended period of time, it's different. There are people who have blown my mind based on the level of their injury and how they have figured out a way to do a task."

As the testing has progressed, the researchers have learned from their subjects and adapted their procedures. In the beginning, patients who couldn't walk were skipping that part of the motor skills test. The testing was expanded to include a 25-question survey asking about the difficulty of specific ambulation tasks in the community. The questionnaire is administered to everyone, including those who can walk. The subjects who had already completed testing before the survey was added were contacted again and given the questionnaire.

All this effort will yield a large set of data that is expected to keep rehabilitation scientists busy for some time. "I don't know the exact number of data points but it could be anywhere from 1,000 to 4,000," Jerousek says. "There should be lots of publications that come out as a result of this during the next several years."

Rehabilitation Measures: Upcoming Webinar!

Have you ever wondered whether you are using the right instruments to assess patients and measure their progress?

This free webinar will review the fundamentals of measurement from a clinical perspective using case examples of rehabilitation for older adults. Topics will include selecting valid and reliable measures for specific clinical situations; understanding the common clinical sources of measurement error and what to do about them; and how to interpret measurements from one assessment, change across two assessments, and change over three or more assessments.



Two cases demonstrating the appropriate selection, utilization and interpretation of assessment instruments will be discussed. The cases will include an older adult with Parkinson Disease undergoing inpatient rehabilitation, and a community-dwelling older adult receiving outpatient rehabilitation.

This webinar has been made possible through funding provided by The Retirement Research Foundation.

Note: Due to high demand, all spaces for the live webcast have been filled. However, we are pleased to announce that a webinar will be available online. For more information about the webinar, please send an e-mail to: rehabmeasures@ric.org.

Fundamentals of Measurement in Rehabilitation for Older Adults

Instructors: Allan Kozlowski, PhD, B.Sc. (PT)
Jenni Moore, PT, DHS, NCS
Date: Monday, August 27, 2012
Time: 12:00 - 1:00 pm (CST)

Recent CROR Dissemination Activities

Manuscripts

Dijkers MP, Bushnik T, **Heinemann AW**, Heller T, Libin AV, Starks J, Sherer M, Vandergoot D. **Systematic reviews for informing rehabilitation practice: an introduction.** *Archives of Physical Medicine & Rehabilitation* 2012;93:912-8.

Bombardier CH, Fann JR, Tate DG, Richards JS, Wilson CS, Warren AM, Temkin NR, **Heinemann AW**, for the PRISMS Investigators. **An exploration of modifiable risk factors for depression after spinal cord injury: which factors should we target?** *Archives of Physical Medicine & Rehabilitation* 2012;93:775-81.

Heinemann AW, Bode RK, Rosenbloom S, Cella, D. **Developing an emotional distress item bank for cancer patients.** *Journal of Applied Measurement*, 2012 13(1), 97-113.

Heinemann AW, Steeves JD, Boninger M, Groah S, Sherwood AM. **State of the science in spinal cord injury rehabilitation 2011: informing a new research agenda.** *Spinal Cord*, 20 March 2012, 50: 390-397.

Lee, J, Dunlop, D, **Ehrlich-Jones, L**, Semanik, P, Song, J, Manheim, L, Chang, RW. **Public health impact of risk factors for physical inactivity in adults with rheumatoid arthritis.** *Arthritis Care & Research*, (2012) +64, 488-493.

Granger CV, Karmarkar AM, Graham JE, **Deutsch A**, Markello SJ, Niewczyk P, DiVita MA, Ottenbacher KJ. **The Uniform Data System for Medical Rehabilitation: Report of Patients with Traumatic Spinal Cord Injury Discharged from Rehabilitation Programs in 2000 – 2007.** *American Journal of Physical Medicine and Rehab*, 2012;91:289-299.

Barnett SD, **Heinemann AW**, Libin A, Houts AC, Gassaway J, Sen-Gupta S, Resch A, Brossart DF. **Small N designs for rehabilitation research.** *Journal of Rehabilitation R & D*, 49(1): 175-186, 2012.

Presentations

Heinemann AW & Raad J. **Improving Medical Rehabilitation Outcomes.** Lecture presented at the Rehabilitation Psychology annual meeting, Ft. Worth, Texas, February 24, 2012.

Deutsch A. **Update on the CARE Item Set. Annual Interdisciplinary Stroke Course – Rehabilitation of Stroke: Techniques, Technicalities and Technologies.** Rehabilitation Institute of Chicago, Chicago, IL; April 13, 2012.

See more at:

<http://www.ric.org/research/centers/cror/publications/index.aspx>

State of the Science Conference (Continued from page three)

functioning is often overlooked.

Similarly, Carolyn Baum, Ph.D., Professor of Occupational Therapy and Neurology at the Washington University School of Medicine, said there needs to be improved measures for executive functioning, which includes ordering and prioritizing tasks and managing time.

She noted that executive dysfunction has not been studied thoroughly even though many people who need rehabilitation services are at increased risk. For example, Baum cited a study of 109 patients with mild strokes that found 64 percent demonstrated difficulty with executive functioning that was only minimally identified by neuropsychological tests.

The subjects showed signs of mild depression, perceived their recovery to be only about 70 percent and were not fully prepared for re-entry into the community. Baum said rehabilitation practitioners need a better understanding of brain mechanisms that influence behavior, performance and participation in daily activities.

Attendee Gregory Worsowicz, MD, chair of Physical Medicine and Rehabilitation at the University of Missouri School of Medicine, said he learned a lot from the interplay of the various professionals

at the event. “The thing I liked was there were different stakeholders whether it was consumers, the funding agency, heavy duty researchers or clinicians like me. We all look at the puzzle through our own glasses. The answers are similar but they are different.”

“They were all aware that we have to make this practical and useable. You can’t do things just because it’s a neat research project,” Worsowicz continued. “You have to have a reason to do it.”



Discussion at the State of the Science Conference

Free Online Continuing Education (CE) Opportunity for Orthotists and Prosthetists

Researchers at the Northwestern University Prosthetics-Orthotics Center (NUPOC) and the Rehabilitation Institute of Chicago (RIC) are proud to announce a new online, continuing education opportunity for all certified orthotists and prosthetists in the United States. Linda Ehrlich-Jones, PhD, RN, (Clinical Research Scientist, CROR, RIC) presents a free, educational module entitled Quality Improvement: What Is It and How Do We Use It? This 15-minute presentation has been approved by the American Board for Certification in Orthotics, Prosthetics and Pedorthics (ABC) for 0.5 continuing education credit. To receive credit, learners are required to pass a 10-question quiz and complete a course evaluation at the end of the presentation.

Content includes a description of the benefits of continuous quality improvement efforts and step-by-step instruction on implementing such a project. Quality improvement initiatives have the potential to improve patient service, increase clinician and support staff effectiveness, and minimize cost by continuously identifying areas for targeted improvement. The outcome of such efforts can lead to improved patient satisfaction with clinical services and products, improved function, and, ultimately, improved quality of life.

ABC has implemented 10 Performance Management and Improvement Standards for organizational accreditation. These standards direct organizations to use surveys to document patient satisfaction; assess the results; create a performance management plan to address deficiencies; and review the plan at least annually.

Learners will be introduced to an example survey, the Orthotics and Prosthetics Users’ Survey (OPUS), which is used to monitor patient functional status, health-related quality of life, and satisfaction with lower-extremity devices and clinical services. OPUS is an instrument that can be used to track patients’ feedback over the course of their treatment by collecting patient data at admission, at device

delivery, and again at a two month follow-up.

As part of the Rehabilitation Engineering Research Center for Prosthetics and Orthotics at Northwestern University, funded by the National Institute on Disability and Rehabilitation Research (NIDRR), Allen Heinemann, PhD, and Linda Ehrlich-Jones, PhD, RN, are leading a quality-improvement research project using the OPUS. This project affords clinical staff an opportunity to receive consultation in implementing the OPUS as part of routine clinical practice. These data allow researchers to provide feedback on programs’ strengths and weaknesses and also provide comparison data with other participating clinics. Each clinic receives expert assistance to create a continuous quality improvement project based on the OPUS results.

REGISTER FOR FREE CE

If you would like to register for the free 0.5 Continuing Education credit, or if you would like to learn more about using the OPUS and are interested in participating in this ongoing research project, please contact Lauri Connelly, Clinical Research Coordinator: lconnelly@ric.org or call (312) 238-1405.

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