

Profile of Carolyn Baum

Because she is driven by a belief that everyone—including those with injuries and disabilities—should live a full life, Carolyn Baum has overseen the transformation of occupational therapy from a clinical specialty into a true science.

Patients getting rehab in the program she directs at Washington University School of Medicine might have their range of motion measured in 3-D before and after therapy. And the therapy might include playing a video game similar to “Space Invaders” with an adapted Wii. They will certainly be assessed with a number of tools she and colleagues have developed that build upon what the patient can do so that they can, as she puts it, “live their lives.”

Baum, Director and Professor of Occupational Therapy and Neurology was recognized for her scientific achievements by the St. Louis Academy of Science in April. Her Scientific Leadership Award was given in recognition of leading Washington U.’s program to the top spot in the nation and her “interdisciplinary approach to neuro-rehabilitation.”

She is described by all as a “glass half full” person. Because she didn’t want to concentrate on patients’ losses, she and her colleagues devised the “Activity Card Sort,” now used worldwide for diagnosis and treatment planning. Shown here, the patient is given a stack of cards showing everyday activities from grocery shopping to swimming to playing with grandchildren. Patients and their caregivers sort the cards into categories: I didn’t do this prior to my injury, I did it and continue to do it, I did it less, I gave it up. The card sort helps individualize treatment. “You find out what you need to help people do. We see what impact the disease has had. And we also see how we can help the families organize daily routines to keep them active. If the activity is meaningful to patients, they continue to do more to help themselves, and show fewer disturbing behaviors. These changes result in less stress on their caregivers.”



Dr. Carolyn Baum, on right, leads a patient and her caretaker through the Activity Card Sort. Photo courtesy C. Baum.

The Activity Card Sort is used in all sorts of NIH studies, often to verify outcomes of treatments such as constraint induced movement therapy in stroke.. Versions of it are adapted to the country in which it is used; Hong Kong’s leisure activity pictures may include Tai Chi, for example. There is a children’s Card Sort, and a set of cards for adolescents is under development.

It seems so simple, but is revolutionary because it leads to quantification. One can imagine all sorts of health care professionals slapping themselves on the forehead and asking “Now why didn’t I think of that?”

Registry points the way to new diagnostic tools

Patients suffering a “mild” stroke with no apparent effect on movement or speech are usually sent home from the hospital after three days, typically without services. But Tim Wolf, instructor in OT and neurology, points out that they did indeed have an insult to the brain, and possibly some disruption in the brain networks.

So Baum, Wolf and colleagues decided to see if these mild strokes had any lasting effect. They were able to draw upon a computerized registry of over 10,00 people who have had a stroke and consented to enter their data and be available for follow-up.

98 ‘mild’ stroke patients took a battery of tests immediately after their discharge and six months later. All the patients in the group had been employed prior to their stroke, but only 63% returned to work. After 6 months, about one-sixth of those working had lost their jobs.

The tests showed that many had disruptions in their cognitive functions. That is, they may have experienced difficulty in planning, or in sequencing steps for a task.

How do these tests show hidden problems? The Executive Function Test, devised by Baum and colleagues, reveals a lot. This test is now routinely given to patients even if their stroke is mild.

In this test a patient must do four tasks:

- Look up and call a phone number
- Cook a pot of oatmeal
- Find their own medicine in a group of pill bottles and show they can follow the instructions on the label with their name on it.
- Find the bills in a pile of mail and pay them in appropriate order.

During the testing the patient may be given “cues” to help them complete the task. The first cue may be verbal, the second gestural, the next may be some physical help, and so on.

Follow-up services can be assigned based upon the amount of ‘cueing’ the patient needs.

When patients who have suffered ‘mild’ strokes take the Executive Function test, those with cognitive loss can be identified and given services they would not have gotten with former standards.

Her approach to problem solving is always creative. Susan Fitzpatrick, vice president of the James S. McDonnell Foundation, recalls a meeting in Oxford to talk about interdisciplinary cooperation. Baum started with a slide giving lists of words used by the different groups. Basic

neuroscientists list included ‘biomarkers, amyloid, potassium channels.’ Cognitive psychologists spoke of ‘executive function and pattern recognition.’ Practitioner’s words included ‘money management and social relationships.’ There was very little overlap in the lists. So with this one slide she demonstrated the need to develop a common language. As Fitzpatrick put it, “Before we figure out how to get there, let’s figure out where we are.”

She is a collaborator by nature, according to Fitzpatrick. In 1996, Baum began planning the research program for the Cognitive Rehabilitation Research Group, funded by the McDonnell Foundation to bring the discoveries of neuroscience to rehabilitation for everyday living. She assembled 32 specialists for her group. Normally such a collaboration would begin with a meeting in which each specialist would present a talk on their current research, answer a question or two, and listen to 31 other unrelated presentations.

At her meeting, she began with a video showing brain-injured people trying to make a cup of tea. For some patients the attempt stretched out for two hours. As each participant watched the struggles, they could begin to see how their specific expertise might be able to help; attention specialists, communication specialists, neuro-scientists could each envision a contribution to solving a very concrete problem.

Baum’s drive and creativity manifested early. A teacher recalled that “she was the one always asking questions I couldn’t answer.” Brought up in a town of 400 in eastern Kansas, restless Carolyn always knew she wanted to go away to college; in high school she had already chosen to become an occupational therapist. Her parents didn’t much believe in college education for women, but she did enroll as a home economics major—and then changed her major.

That self-reliant rural upbringing, with 4H competitions in pie-baking and dressmaking, gave her life skills much appreciated by her daughter and friends. When her daughter, Chicago attorney Kirstin Sumner, acted in high school musicals, “Mom Baum” made the costumes for Kirstin and her friends. She sewed most of Kirstin’s prom dresses. And the Baum apartment was a home away from home for Kirstin’s friends during her Washington U. student days. They would come for a fabulous Sunday night dinner and head back to the dorm with a ‘care package’ of leftovers. Then “Mom Baum” would finish editing her book or grading her papers.

Daughter and mother form a mutual admiration society. Baum says raising her daughter as a single divorced mother is her proudest accomplishment. Kirstin says she is “the luckiest person ever” and her Mom is “a true inspiration—a person of incredible energy who never shies away from new experiences.” She recalls that as a teenager in 1982 she accompanied her mother as she led a group of therapists to rural China to talk about occupational therapy. “There was fearless Carolyn running around China just after it began to open to the west.”

China was just the beginning. Baum has traveled the world in her professional capacity, and goes to Australia every other year as a visiting scholar at the Stroke Center of Australia. Everywhere she goes she makes friends as well as professional contacts. In the late 1990’s she decided to rent a villa in the tiny Umbrian village of Panicale. Having made friends with many



The princess of Malaysia visits Carolyn Baum in Panicale Italy.
Photo courtesy of C. Baum

of the people living there, she returns each year and cooks a huge Thanksgiving dinner—for which she brings the cranberries, sweet potatoes, and pecans. One Panicale native attended Kirsten’s wedding five years ago. The princess of Malaysia, whom Baum had met on her business travels, vacationed with her in Panicale in 2004.

This ability to relate to people shows up again and again when people speak about Baum. Linda Cottler, Professor of Epidemiology, became acquainted with Dr. Baum's skills and compassion when Cottler's mentor had a stroke. Baum took on the role of the mentor’s OT and personally worked to devise a care plan that would help a very creative researcher find her way back. “It was very touching to see her compassion and her dedication to someone in the WU community. She often checked on her to make sure things were going okay. “

Tim Wolf, who earned his OTD with her and then joined the faculty, speaks of her mentoring style. “She is good at understanding each person’s strengths and weaknesses. She learns where you want to go, and helps you get there. She helps you find the resources you need—perhaps money for a course, salary support to lessen a teaching load, or help in building a relationship with a person in another department.”

Baum credits her own mentors. When Washington U. recruited her to direct the Occupational Therapy clinical services in 1976, she was a clinician and experienced manager. She was not a scientist and had no plans to be one. But when the late Dr. Leonard Berg observed what she was accomplishing with his Alzheimer’s patients on the neurology floor, he asked her about the science behind her treatments. She went to the literature and found it all organized around what people could not do. Together they decided to find ways to help patients with neurological impairments “live their lives”, and to do it in a scientific manner. She began collaborating with a new psychology Ph.D., Dorothy Edwards, to devise new measurement and treatment tools. Eventually the time came when she wanted to follow her own interests. Edwards suggested she get a Ph.D. “And so,” says Baum, “I did.” She obtained a Ph.D. in social work at the age of 50.

The science has burgeoned since then. The School of Occupational Therapy now has 11 research labs, and is submitting a plan to give its own Ph. D. degree. The labs use cutting edge technology, from GPS to MRI. As faculty member Jack Engsborg puts it, “My human performance laboratory is probably the only one in an occupational therapy school in the world.” Since Engsborg is a biomechanist with an engineering degree focused on mechanical engineering, it is easy to see why only someone with scientific vision would put him on the faculty of an institution dedicated to helping people do their everyday tasks.

Each laboratory lists collaborators in at least five other departments.

Applying Lab Findings to Therapy

It often takes a lot of learning for a patient with neurological injury to be able to perform once-routine activities like putting a can on a shelf. Conventional therapy has the patient do the motion 40 times in an hour. But lab research on animals has shown that 300 reps per hour is the required number. That's a lot of cans to stack. And stacking cans is not very rewarding.

Enter the video game. Jack Engsberg of OT is collaborating with Caitlin Kelleher in computer engineering to devise games that people can play at home to practice the motion they need. Suppose a patient needs to improve wrist mobility. A Wii controller attached to the wrist could steer a helicopter over buildings of different height. After a time, the helicopter might need to refuel mid-air. One patient who hadn't used her arm for 17 years after her stroke played such a game about an hour a day for six weeks (about 1000 reps/day) can now raise her arm and even move it to catch a falling object.

The games are individualized and updated to maintain interest. At present the computer scientists are creating a language for therapists, so they can write their own games based upon what interests the patient.

From the lab to clinical application—and it works.

Baum is proud that in her second term as president of the American Occupational Therapy Association from 2004-7, she and a group of like-minded colleagues made sure that theirs is a professional society rather than a trade association. Science will be a bedrock value as they enter the second century of their profession.

She has authored hundreds of papers, has been influential in national policy-making, and her list of honors stretches well past a page. But she sums it up by saying she hopes to be remembered as “One who made a difference in the lives of people with disabilities.”