



THE *heart* OF THE SCIENCE

PEOPLE IN RURAL NORTH CAROLINA COMMUNITIES HAVE MADE
DECADES OF GROUNDBREAKING RESEARCH POSSIBLE.

BY MICHELE COHEN MARILL

When Dr. Joanne M. Jordan first visited Johnston County, North Carolina, in

1987 as a young rheumatologist, she discovered communities of warm-hearted people. Most lived along country roads amid tobacco fields and farms. Those who didn't till the land worked in nearby textile or lumber mills. Years of manual labor left many of them with arthritis.

Dr. Jordan, new to the faculty of the University of North Carolina at Chapel Hill (UNC), was conducting arthritis assessments as part of a rural health research study. She was

often the first doctor to pay attention to their aching joints.

Dr. Jordan felt drawn to this vulnerable population and their willingness to be a part of research. She saw an opportunity for something bigger. About three years later, she launched a long-term study — the Johnston County Osteoarthritis Project, or JoCoOA project, for short — with support from the Centers for Disease Control and Prevention (CDC). Today, it is one of the longest running arthritis studies in the nation. In a span of 28 years, it has produced major findings about risk factors, prevention and treatment of OA, which affects an estimated 31

million Americans. It is the source for about 180 published journal articles and more than 40 offshoot studies by researchers worldwide who have gathered insights about how OA changes over time, who is most susceptible and the effects of lifestyle.

The longevity and impact of the landmark project were made possible by the people of Johnston County. Medical research like this relies on participants who are willing to stay engaged for years — and Dr. Jordan found the Johnston County folks were all-in.

“People were so eager to participate for the value of helping someone else,” she says.



Dr. Joanne M. Jordan (right) launched the JoCoOA project, now in its 28th year.

JoCoOA Firsts

From the outset, study participants were statistically representative of Johnston County. About 30 percent of the first 3,200 participants were African-American, making it the first long-term, ongoing study to identify some important racial differences. Here are two key findings:

» Symptoms, biomarkers and joint shape related to OA differ by race and gender.

» African-Americans are just as likely as whites to have hip OA, even though they have lower rates of hip replacement surgery.

RECRUITING THOUSANDS

To get the project underway, the research team reached out to randomly selected residents aged 45 or older. Initial recruitment brought in about 3,200 people, 70 percent of whom did not have OA when the study began.

Lynn Joyner, one of the first local interviewers, drove back roads with a clipboard and map in the days before GPS, visiting new participants. People literally opened their doors to the researchers. “I’ve had participants play the piano for me, sing hymns or show off their gardens,” she says. “To build relationships, you’ve got to sit down and talk.”

Those relationships led to a strong and long-term commitment to the project. About every five years, the participants visit the clinic for a two-hour-long exam, which includes X-rays, blood and urine samples, and tests that measure range of motion, foot-arch height and gait.

That long-term commitment is key to OA research.

“Osteoarthritis is a disorder that evolves very slowly, so we need long-term studies,” says Timothy McAlindon, MD, chair of rheumatology at Tufts University School of Medicine in Boston and a leading OA researcher.

“To be able to maintain a [group]

over that period of time provides a lot of unique insights that are just not available any other way,” says rheumatologist Amanda Nelson, MD, assistant professor at UNC and a co-principal investigator for the JoCoOA project.

The legacy of discovery makes Johnston County residents proud. “We let them know they’re part of something that’s bigger than any of us,” says Dr. Jordan. “Giving back is part of the bedrock of what we do.” Dr. Jordan, still an active researcher with the project, is now vice dean for faculty affairs and leadership development for the UNC School of Medicine.

THE SCIENCE: FALL PREVENTION

One of the people at the heart of this work is

Diana Futch. At 74 years old, she’s agile and energetic, and her philosophy is to just shrug off aches



and pains and keep going. She has osteoporosis and shooting pain at the base of her thumb, likely from a repetitive motion injury caused by twisting a tool for some 20 years at a defunct textile factory. “It feels like a little fire’s running through it,” she says, as an explanation but not a complaint.

Diana, who once saw her elderly mother fall and break her hip, participated in a JoCoOA sub-study that tested ways to prevent falls. For six months, she exercised with light weights on her ankles to build strength in her legs and practiced balance training. A physical therapist evaluated her with balance tests, questionnaires and other assessments.

The researchers found that symptomatic osteoarthritis in one hip or knee joint increased the risk of falling by 53 percent. The risk rose with each additional affected joint, so that someone with OA in both knees and both hips was 85 percent more likely to fall than someone without OA.

Eventually, researchers hope to show that certain strength and balance exercises reduce the risk of falls.

Even now, Diana occasionally wears the ankle weights. The balance advice also stuck with her. “I think it made you more aware of watching how you walk to keep from stumbling,” she says.

THE SCIENCE: OVERLAPPING CHRONIC DISEASES

Della Gullatt

took part as an interviewer in JoCoOA before she became a study participant. At 73, she belongs to a line-dancing group called Sassy Feet and rides an exercise bike an hour a day while she watches television. If her knee gives her trouble, she takes a rest and then gets back to her activities.



Over their lifetime, 1 in 4 Americans will get hip OA.
— JoCoOA, 2010

“It’s so easy to get into a pattern of watching TV where you don’t have to move,” says Della. “You just have to push yourself. I know that it’s important to move with arthritis.”

Della has long struggled with her weight, and after battling breast cancer in 2010, she developed diabetes. The same messages about eating well and exercising apply to both diabetes and arthritis, she says.

In fact, the overlap between arthritis and other chronic conditions has become a recent focus of JoCoOA research. Joint pain is sometimes the hidden barrier for people with diabe-

tes or heart disease who need to stay physically active, says Dr. Jordan.

“Frequently, arthritis isn’t discussed at all in a physician visit,” she says. “If you forget about the arthritis, you’re missing the opportunity for intervention.”

The consequences can be significant. JoCoOA researcher Becki Cleveland, PhD, found a higher rate of mortality among participants with knee OA than a comparable group without it.

“What everybody has come to realize more clearly over time is that diseases don’t occur in isolation,” says the CDC’s Dr. Helmick. “Osteoarthritis, in particular, does not occur in isolation. Half the people with heart disease, half the people with diabetes and a third of the people with obesity have arthritis.”

Della, who has two sisters with serious health issues, knows how important it is to have a healthy lifestyle. The JoCoOA project provides encouragement. “Everything is geared around eating right and exercise,” she says.

THE SCIENCE: REDUCING PAIN

Della pushes herself to stay active, knowing that it will help her arthritis. But for many people, the pain of OA leads to despair that feeds a downward cycle, preventing them from getting the physical activity that will make them feel better.

One study added some hope to the equation: In it, women with knee or hip osteoarthritis followed an online training program that taught pain-coping skills: how to relax, how to shift to more positive thinking and how to pace their activity with moments of rest. They had significantly less pain after eight weekly sessions than participants who didn’t learn the strategies.

The study showed that an online program, which provided automated instructions in a woman’s voice and was designed to respond to the user’s feedback, can be effective, even with older adults who aren’t computer-savvy.

“We approximated the experience of talking with a caring, well-trained



Study participants visit the clinic about every five years for a range of tests and measurements, including foot-arch height.



Yvonne Golightly, PhD, a physical therapist and co-principal investigator, or lead, of the JoCoOA project, measures a patient's leg.

and responsive therapist who was invested in helping them learn skills they could use to reduce their pain,” says Christine Rini, PhD, director of Cancer Prevention and Control at the John Theurer Cancer Center of Hackensack (New Jersey) University Medical Center, who led the study.

Della followed the program and tracked her pain levels. “The suggestions they gave did help,” she says. She’s not that comfortable with computers, but she was able to manage the tasks.

THE SCIENCE: WORKING AND WALKING WITH EASE

Arthritis can make working a challenge, so JoCoOA set out to help people on the job. One study evaluated the impact of the Arthritis Foundation’s Walk With Ease program on workplace limitations. After six weeks of walking, stretching and strengthening exercises, the participants reported better mobility at work. A year later, they had maintained their progress and increased their weekly walking on their own.

Lead researcher Leigh Callahan, PhD, the Mary Link Briggs Distinguished Professor of Medicine at UNC and a longtime Arthritis Foundation-funded researcher, emphasizes that

you can get the same benefit of a half-hour walk by walking just 10 minutes three times a day. “We all know walking is good for you,” she says. “This program focuses on how to give people the tools and tips to be safe and appropriate with arthritis.”

*By age 85,
50 percent of
Americans will
get knee OA.*

– JoCoOA, 2008

THE SCIENCE: ROLE OF MICROBES

More recent JoCoOA studies promise to reveal other critical insights into the mysteries of OA. With funding from the Arthritis Foundation, Richard Loeser, MD, director of the UNC Thurston Arthritis Research Center, is searching for the connections between the microbiome, or bacterial ecosystem, and OA

among people who are overweight or obese. Microbes that help break down food may contribute to inflammation – and affect how we gain or lose weight.

“[Previous] studies show that obesity is related to differences in the [gut] microbiome and that high-fat diets can alter your microbiome,” says Dr. Loeser. “Since obesity is clearly related to OA, we thought there could be a connection between obesity, diet, the microbiome and osteoarthritis.”

The JoCoOA participants stick with the project as a way to help others with the disease in the future. For Georgene Capps, a social/clinical research assistant for JoCoOA for 18 years, they already are helping by example and inspiration. Georgene, 65, was diagnosed in her early 30s with ankylosing spondylitis, a type of arthritis that causes back pain, stiffness and can lead to spinal fusion and immobility.

“Here’s what they’re teaching me – keep on going, even when you don’t feel like it,” she says. “They don’t give up.” TM

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