



Professor Linda Tickle-Degnen and her graduate student researchers are exploring the communication hurdles faced by those with Parkinson's disease and how they can be overcome.

Face Time

BY ROBERT BOCHNAK ILLUSTRATION BY JAMES STEINBERG

THE MAN IN THE VIDEO SITS ALONE AT THE Tufts Health Quality of Life Lab speaking to an off-camera voice about, of all things, a wedding he recently attended. On the surface, there's nothing unusual about the conversation, but as the tape goes on, a curious flatness in his voice and manner become apparent. Linda Tickle-Degnen, lab director and professor and chair of the School of Arts and Sciences occupational therapy department, lets the video run for a few minutes before she begins pointing things out. She starts with the man's lower body, noting that he hasn't moved or otherwise repositioned himself since the interview began. Next, she calls attention to his left hand, which has been trembling slightly. She ends with his face, but no explanation is necessary: he's remained almost expressionless.

To the untrained eye, the man appears disinterested, even bored. But to Tickle-Degnen, it's clear that the subject, a Parkinson's patient, is exhibiting "facial masking," a symptom in which facial muscles become immobilized and the patient has what can best be described as a blank expression.

"The face is the primary way we communicate with other people," says Tickle-Degnen, who has been researching nonverbal and verbal communication among people with Parkinson's and other diseases for the past twenty years. "We tend to believe the actions of a person more than their words if we feel there is a discrepancy between the two. So, a person with Parkinson's disease may be talking about their feelings and saying that they are really enjoying life but may not be believed."

If the goal of occupational therapy is to provide

“skills for the job of living,” then the work being done at the Tufts lab could be instrumental in helping those with Parkinson’s express themselves and be understood. Right now, the research is focused on improving communication in an area where many such patients have important relationships—the healthcare system.

“Practitioner-patient interactions are social relationships,” says Tickle-Degnen. “If a neurologist, speech therapist, or occupational therapist gets the feeling that the person they’re working with is disinterested or depressed, then this relationship can be affected.” Tickle-Degnen notes that practitioners sometimes “fail to talk to the person about their feelings because facial masking consistently causes a perception of depression, deception, hostility, and apathy in practitioners—even when they are experts.”

“If there was a way that we could train practitioners to better detect how positive or negative a person was feeling,” she adds. “We could help strengthen these relationships.”

Parkinson’s symptoms include tremors, limb stiffness, and difficulty moving and maintaining balance. If you add the vocal challenges of Parkinson’s to the mix—some, like the man in Professor Tickle-Degnen’s video, may also have difficulty modulating the tone of their voices—it would seem as if the obstacles to effective communication with the outside world are insurmountable. But Tickle-Degnen would disagree, and she has about 500 reasons why.

ANATOMY OF A SMILE

There are at least 43 muscles in the human face. These muscles, working in concert with other parts of the body, help people to smile, frown, grimace, and express subtle feelings. The key to these movements can be found in the substantia nigra, a layer of gray matter within the brain that produces the neurotransmitter dopamine. Dopamine allows human beings to make facial expressions, as well as walk, run, perform hand gestures, and carry out other bodily movements in a coordinated way. But when dopamine-producing cells are damaged, the result can be an inability to control motor function. This motor loss is a key feature of Parkinson’s disease, a condition that affects 1.5 million Americans and is the second

most common neurodegenerative disease after Alzheimer’s.

While emotions may not be “written on the faces” of many people with Parkinson’s, it is possible to find out what they are feeling if you look beyond the “masking” and focus on what Tickle-Degnen calls the “reliable cues”: the ones that don’t change even with facial paralysis.

As part of the study, Tickle-Degnen and her team of researchers have conducted and videotaped 500 interviews with Parkinson’s patients. A typical interview consists of a series of “positive” (“what do you enjoy doing?”) and “negative” (“describe a frustrating event that occurred last week”) response questions. Subjects are then rated using a coding system Tickle-Degnen developed based on her own research on interpersonal rapport and on facial expressiveness done at San Francisco State University. When using the coding system, known as the Interpersonal Communication Rating Protocol (ICRP), coders look at, among other things, the frequency with which

subjects express “nonverbal cues.”

“For all the interviews, we analyze facial behavior, body movement, voice, and we also do text analysis,” says Tickle-Degnen. “I ask them about their feelings: if they are happy, unhappy, and so on. We’re looking for particular cues.”

Sometimes feeling is expressed in an obvious way through facial expressions—a smile, frown, or furrowed brow—and sometimes the cues are very subtle, involving just the slightest movement of a facial feature.

“When you lift up your cheeks and crinkle your eyes, this is an indication that you feel genuine happiness. Without the crinkling of the eyes, it may mean that you’re trying to pose that you’re feeling happy. When you raise both of your eyebrows, it can mean that you’re surprised,” says Tickle-Degnen. “Often, when the part of your eyebrows nearest to your ears (the lateral part of your eyebrows) is depressed and when the inner part of your eyebrows is a little bit lifted, this is a sign of sadness.”

Beyond feeling and mood, personality



Professor Tickle-Degnen (left) with psychology graduate student Kathleen Bogart

is also expressed through the body, according to Tickle-Degnen, “People who are very sociable and extroverted tend to use large motions with their hands and tend to be very facially expressive, meaning that their face is showing a lot of motion. I did not say *emotion*, but motion: their faces are in motion. When they tend to be more introverted or shy, they tend to [move] less in their whole body. Their body is a little bit more quiet and their facial expression is quieter.”

Although the research is still being col-
lated, already some critical findings have emerged.

“We’ve found that when we ask positive questions, the facial masking in our subjects is less intense and they are actually able to smile more than when asked negative response questions,” says Tickle-Degnen. “This is really important for people who work with Parkinson’s patients, since many tend to do what is called a ‘problem-oriented interview.’ They ask ‘what problems are you here to talk to me about today?’ Typically, nobody asks people with Parkinson’s about

positive things, because there’s not much positive emotion on their faces. Practitioners and other people in their lives will just ask, ‘what’s wrong?’ or ‘what’s bothering you?’”

According to Tickle-Degnen, “If you want to figure out how a person with Parkinson’s is feeling, the mood they are in, you have to ask questions about things that make them happy.”

The next step is to train practitioners how to interpret their patients’ nonverbal cues as well as to get them to focus more on what they are actually saying—a practice that goes against the way people intuitively read one another, which is visual.

“Perceptions of sociability are biased based on the stiffness and rigidity that can result from Parkinson’s,” says Heather Gray, a post-doctoral fellow in the Health Quality of Life Lab whose research involves “training” Tufts graduate and undergraduate students to recognize certain cues in people with Parkinson’s. “People see a person who looks ‘masked’ and conclude that the person must be very shy or unhappy, which is often

not the case. With the Tufts students, we’re teaching them about the reliable cues that remain. We explicitly tell them that masked faces are caused by the disease and not from any changes in personality. We also tell them that there remain very good clues to personality in Parkinson’s—the words people say. It seems common sense and, of course, it is, but our natural instinct is to really base our judgments on the nonverbal cues. So we’re trying to change that.”

Heather Gray’s research may impact how practitioners communicate with their Parkinson’s patients.

“We’d like to continue our research with the students and then see what comes next,” says Gray. “It would be nice to work on disseminating this research to an audience of treatment professionals, Parkinson’s patients, and other interested folks who might not read scholarly journals.”

BEHIND THE MASK

Once the coding process for the interviews is complete, short clips of them are shown to Boston-area doctors and therapists, whose own responses are then studied and analyzed.

“We ask the practitioners to tell us how happy, depressed, or cognitively intact they think the person is. We also ask them to tell us how sociable they think the person is and what mentally challenging activities might he or she be interested in,” says Tickle-Degnen, whose research has been supported by the NIH’s National Institute of Neurological Disorders and Stroke and its National Institute on Aging. “These are not judgments about how much smiling the person is doing, but more social level or diagnostic judgments.”

This type of information is critical, since judgments like these play key roles in treatment decisions.

“Practitioners need to figure out if a patient is depressed and needs medication or if the person has dementia and requires a related intervention,” says Tickle-Degnen. “Occupational therapists need to make decisions about the social vitality of the client when they decide what types of activities—whether they are social or solitary—the person should be involved in. If someone’s face and voice are not giving off signals easily, then delivering proper treatment can be

Beyond Parkinson’s

While Parkinson’s disease is a research topic of many students at the Health Quality of Life Lab, students are also studying facial paralysis caused by other disorders. Kathleen Bogart, a GSAS psychology graduate student, is researching nonverbal and verbal communication among people with conditions that result in facial paralysis, such as Bell’s Palsy and Moebius Syndrome, a rare congenital disorder.

“My work is very similar to the Parkinson’s research,” says Bogart, who has Moebius Syndrome herself. “We videotape people with facial paralysis and examine how they move their faces.”

During the taped interviews, subjects are asked what it was like growing up with facial paralysis or, if it was acquired through disease later in life, how they have coped with it. “We also ask them more specific questions about how facial paralysis affects social interaction and strategies they use to communicate without facial expression,” says Bogart.

Bogart, like fellow researcher Heather Gray, will then show her video clips to several Tufts students to find out how a general population perceives those with facial paralysis and also how these particular populations compensate for their lack of facial expressiveness.

“In the long-term, I expect to find that people with facial paralysis use gestures and body language more,” she says. “This is actually different from what Linda is finding, because people with Parkinson’s are not able to compensate with their bodies. Fortunately, people with facial paralysis usually can.”

difficult. But if they know what cues to look for and the types of questions to ask, they can know their patients much better.”

Although Tickle-Degnen’s research takes place primarily at the Tufts lab and in Boston-area hospitals, the scale of the study is global. She is also studying how practitioners from Taiwan perceive patients with Parkinson’s. Tickle-Degnen, who has advanced degrees in both occupational therapy and psychology, says their findings show practitioners may “think they’re being objective in their diagnoses, but that they are being driven by cultural norms in determining depression or dementia or lack of it.”

“We are studying how cultural norms affect people’s perception of facial masking, and also gender norms, because people expect women to have different kinds of non-verbal behavior than men,” she says. “People expect women to be more expressive, and that’s the world over. However, in western countries, like America, women are expected to be really smiley. Not so much in Asian countries, although that’s changing.”

In addition to helping healthcare practi-

tioners, Tickle-Degnen is beginning to use the research for the direct benefit of Parkinson’s patients as well. She has given talks to people with Parkinson’s at Newton–Wellesley Hospital and the Harvard Club, among other places, on how to make their emotions more explicit in their daily interactions with people. And, as part of a collaboration with neurorehabilitation and movement disorder clinics at Boston University, she has conducted a randomized control trial that studied three groups of Parkinson’s patients: one that was given medication only and two that were given medication and different intensities of “self-management rehabilitation.” This included facial exercises that helped patients retain their facial expressivity to some extent.

“The primary thing we’ve measured so far is quality of life,” says Tickle-Degnen. “And those people who received rehabilitation reported that their quality of life was greater. This is in terms of their ability to communicate with others and to not be misunderstood, and to move around the community to perform their daily life activities.”

Tickle-Degnen presented these research

results at the 2009 American Occupational Therapy Association Conference in April and at the International Congress of Movement Disorders, a neurological convention, in Paris in June.

GETTING THE WORD OUT

In the future, Tickle-Degnen hopes to work with more graduate and undergraduate students from other Tufts departments, and is currently pursuing collaborations with faculty from the departments of psychology, computer science, mathematics, and mechanical engineering.

“When researching a problem like Parkinson’s disease or communication in general, it takes a lot of time to measure just one or two elements of what you’re studying,” she says. “Now, if I wanted to also study the mechanical aspects of the face, which I think influences social perception, that would take another career. But here at Tufts we have computer scientists and mechanical engineers who study the mechanics of how things move and work. We have psychologists who study social perception. This problem has mechanical, psychological, and social aspects. It’s really important to collaborate because when you’re dealing with a problem, the problem is multi-dimensional.”

Tickle-Degnen and her research team have published a number of articles in professional journals such as the *American Journal of Occupational Therapy* and *Psychology and Aging* and have been interviewed for national media outlets such as National Public Radio (NPR) and the *Boston Globe*. She believes the first, best step in shrinking the communication divide between practitioners and those with Parkinson’s is sharing what she and her researchers have discovered. But she concedes that getting the word out is just the beginning.

“It’s wonderful to have people read the articles we have published,” she says. “It’s another thing for people to actually use what we have found. Instead of seeing this as a negative thing, I see it as a challenge, to get out there and help people understand why this work is so important for people with Parkinson’s.” **AM**

The Homefront

People with Parkinson’s, even in its advanced stages, can lead rich, fulfilling lives. They may just need a little help. This assistance usually comes from family or other caregivers, and these are another set of relationships that Linda Tickle-Degnen plans to explore.

“We’re starting a pilot project soon which will look at how people with Parkinson’s interact and get cognitive, social, and self-care tasks done with their spouse, partner, or other caregiver,” she says. “For example, a cognitive task for those with Parkinson’s is sorting medication. When you have 13 to 16 daily medications, it’s quite a cognitive feat to figure out how many you need to take each day and if they need to be taken with or without food. We also plan to look at how other tasks get done like getting dressed. Simply putting on a shirt is very difficult for people with Parkinson’s because they have reduced rotation in their trunks.”

Like her practitioner-related research, this upcoming project will include videotaped interviews but will also feature couples or caregivers.

“I’ve published a number of articles on the rapport necessary to get tasks done with another person,” says Tickle-Degnen of the research. “There are many nonverbal and verbal behaviors that are associated with higher rapport versus lower rapport, and I’ll be looking at how people who have severe facial masking work with their caregiver compared to a group that has less masking.”

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