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The engineer and the neurologist

Rosalind Picard only wanted to develop a bracelet that measures the stress of autistic people. Then it turns out it might save lives. But this is where the problems begin.

By Eva Wolfangel

Rosalind Picard, an electrical engineer at the Massachusetts Institute of Technology (MIT) in Cambridge, USA, could not know that student stories would lay down the pattern in her life when in June 1999, a young man came to her doorstep. And she had no idea how much coincidences like this would determine her success. Fortunately, it was in her nature to be open to it.

At this moment in June 1999, Rosalind Picard is wondering whether the new field of research of wearable computers that she helped to build should actually be called wearable computing - "Do we really want to go with the abbreviation WC?" - when one of her students knocks and shyly asks: "Can you help my brother? He can't understand emotions, he's autistic." Picard has been working for several years now on how computers can recognize people's feelings. The path through facial expression seems promising to her; using photos, her algorithms learn for example whether a person is happy or sad, angry or disappointed.

She is happy to see the young man at her door and invites him in. Finally, there is a good application for her research! Autistic people such as her student’s brother could benefit from computers deciphering people's emotions. Her enthusiasm is greatest when she feels she is doing something good, so she intensifies her research and equips not only her student's brother, but also numerous other test persons with small computers and an application that should tell them what their counterparts are feeling by means of their facial expressions.

Eighteen years later, Picard is standing in a hall in Heidelberg in front of thousands of participants at a computer science conference and reporting on this meeting; the beginning of her success story. She knows how to captivate her audience; she makes dramtic breaks and her listeners hang on every word. "We had 70 percent accuracy at that time ", she calls into the hall with an accentuated "at that time" and a grin on her face: 70 percent of the emotions were correctly interpreted by her system at that time. "Today", she continues, "today we have measured more than four million test persons from 75 countries." The logo of a company appears on her slides: Affectiva. Picard co-founded this company, which holds the world's largest emotion data store. "Today we have 90 percent accuracy," she advises the conference. And that's just the beginning of the story.

A conference break gives me the opportunity to pluck Picard's sleeves, but not immediately. She is surrounded by young researchers; all have questions for her, and everyone dreams of saving the world one day like their great idol. She steers the cluster to the coffee bar, very slowly, making sure not to miss a question; her concern that younger people benefit from her experiences is obvious. Shortly afterwards, those of us who manage to meet her in the tranquillity of an adjoining room will learn of her doubts. "It's not that easy to determine emotions by facial recognition," she says. "Try it here." And indeed: a false smile is interpreted by the app as real cheerfulness, and if one puts on a look of concentration the app interprets it as dissatisfaction. The algorithms are guided by similar patterns as humans but lack context and intuition, so misinterpret more than most people. "A forehead wrinkle can mean concentration as well as anger," she adds,"or just age." Fortunately, the story continues.

Back in 2007: Rosalind Picard’s career at MIT advances rapidly: She is now a full professor and famous in the Computer Science scene for her research on wearable computing. But one thing has never changed: she takes every request seriously, and has never forgotten how to listen. So, one day, one of her test persons, an autistic man, dares to tell her the truth: She is on the wrong track. "I have no problem understanding your emotions," he said,"but you don't understand my feelings."

At this point she realizes that an autistic people are not going to be helped by algorithms that read facial expressions. "Autistic people often seem to be very calm on the outside, but they are upset inside", says Picard. Even for close friends and relatives their facial expressions remain mysterious. So Picard begins experimenting with wristbands that assess stress levels by measuring sweat on the wrist; the same technology used for lie detectors: If someone is stressed or excited, then the so-called electrodermal activity grows and the skin becomes moist; often imperceptible to that person. Her experiments look promising; she finds that stress correlates very directly with sweat on the wrist - when a student knocks on her door just before Christmas 2007. "Can you help me? I'd like to know when my brother's stressed out."

Rosalind Picard is a scientist who does not research for the sake of research. Every meaningful use case of her technology drives her. So she invites the student in, and finally gives him two of her measuring instruments to use with his brother over the Christmas holidays, "Take both, in case one of them fails." When the young man returns to the laboratory in January, she is surprised at the measured values. The student had misunderstood the instruction: instead of one bracelet he had used both at the same time. And while the data curve on one wrist was quite even, Picard is shocked by an enormous curve on the other. "The kid was stressed like I'd never seen him before." How is it possible that stress changes electrodermal activity on one wrist only? Picard is confronted with a mystery. She asks her student: "What happened on Sunday at 2:00 pm?" The student kept a diary, looked up and said: "Soon after that, my brother had an epileptic seizure."

Epilepsy? Picard has no idea what that is and spends a whole night on Google. Then she starts to read neuroscientific articles. She is buried in literature and finds that electrodermal activity correlates not only with stress but with activity in the autonomic nervous system. She reads about parasympathetic and sympathetic effects; thoughts whirling through her head. But what does this peak on one wrist mean? She doesn't find anything about that in the literature. She finally dares to ask her intern, who happens to be the daughter of a leading epilepsy researcher at the nearby Boston Children's Hospital. Maybe they could talk to each other? The doctor agrees to a meeting immediately. "I was so terribly excited," confesses Picard. Will the doctor take her seriously? Will he be open to the technology? Will they speak the same language at all?

Same language? That's a strange question for Tobias Loddenkemper, the director of Clinical Epilepsy Research at Boston Children's Hospital. Of course not! "We are both highly specialized, each in their field", he believes. But from his point of view it was a stroke of luck that these two different scientists came together. "I wish we'd met earlier," he says. For him, this computer scientist standing excitedly in his hospital door at the beginning of 2009 could be providing an important piece of the puzzle for a research project he had begun in the 1970s but that had come to a standstill. "We knew this signal, we knew this change in the autonomic nervous system was a Sudep marker." Sudep stands for Sudden Death in Epilepsy; the sudden death after an epileptic seizure. Until then, this death was a mystery for the researchers. When exactly did it happen? And why? The problem was that these changes in the autonomic nervous system could only be measured with complex structures in the clinic. "We had neglected that signal." But although Loddenkemper suspected that it could be verified by EEG, the proof was still missing. "And we can't send patients home with an EEG on their heads," the neurologist says. "Especially for children this would be a stigma and not practical."

The situation was tricky: it seemed as if there were markers predicting death, but they could not be measured practically. "It was our good fortune that Rosalind found us," says Loddenkemper.

In 2010, the proof was finally found: Samden Lhatoo, Professor of Neurology at the University Hospital in Cleveland, used data from those who died in hospital to show that certain, conspicuously flat EEG signals shortly before a seizure, also seemed to predict sudden death. Further experiments showed that this tip in the electrodermal skin reaction that Picard could measure with her bracelet correlated very highly with the flat EEG signal that Lhatoo had described. "It's my greatest hope that Roz's sensor can detect seizures and tell us how high the risk of someone dying is,"says Loddenkemper.

With that information, it is possible to save lives, he hopes. From a lot of data from the past, he knows that these sudden unexplained deaths usually occur when the people affected are alone. Something about the presence of other people seems to prevent death. What exactly, science does not know yet, only the correlation is known: anyone who suffers a seizure in company is less likely to die. Picard explains this from her reading of neuroscientific studies as follows: "A place in the brain is influenced by the seizure in such a way that people forget to breathe. All you have to do is talk to them and they'll breathe again!" She founds another company, Empatica, and launches a measuring device that predicts such seizures thanks to various sensors and artificial intelligence, and distributes the device to volunteers.

"And then one day my heart stopped," she says in her lectures, and her listeners hold their breath when she reads the mail sent to her by a mother of an epileptic child: "The bracelet is amazing! We had an alarm this morning, ran into the nursery, and there she lay face down: She had a seizure and stopped breathing. We turned her over, and now she's lying there rosy and asleep."
Picard takes a short break.
"The device saves lives."

Does it save lives? Loddenkemper desires nothing more. "I don't want to get these calls anymore from families saying 'My child is dead! I didn't know she was having a seizure!' " He falters briefly. "That's the worst thing that can happen to a doctor." He would love to say that the device saves lives. He also suspects that it does. But he temporizes: "We can't say it for sure." He knows of many deaths from epilepsy where the patient was alone. And he knows Picard's stories about how the device set off an alarm and saved a patient. But would that patient really have died without the alarm? And would the others not have died if someone had been with them? "Recently, a patient with a wristband on his wrist died," he says and sighs. The device had set off the alarm, but the child's parents couldn't get to him fast enough. In this case, the device thus verifiably predicted death correctly, but Loddenkemper would have preferred to waive this proof.

He is also skeptical as to whether simply talking to the patients as Picard propagates is sufficient. "Responding is always the first thing you do – but no one would ever leave it at that." People give medication, they resuscitate the victims, they call a doctor. "We don't know exactly what helps," he says.

One might see this as an exaggeration when Picard talks about saving lives, but one can also see that if Picard hadn't been as she is - enthusiastic, full of zeal and empathy for her subjects, if she weren't so open-minded, if she didn't give a chance to every coincidence, this device would not have been built so quickly. Many of her colleagues in Computer Science are particularly good at building things for only one reason: because it is possible. Many people ask the question about its implications far too late - or not at all. Loddenkemper is convinced: If Roz Picard's thoughts hadn't been caught by the strange imbalance of the data, and if she hadn't happened to replicate an old discovery of brain research, it wouldn't have come so far.

Some accuse Picard of enriching herself on other people's suffering. She has founded two companies and the first, Affectiva, sells emotion recognition to advertising companies for profit. Targeted advertising instead of helping autistic people? The slight wrinkle on Picard's forehead deepens. A sign of trouble, her app might say. "Founding a company always seemed like I was going to switch to the dark side," she says."But we needed the best people, and we couldn't get them otherwise." The money from the marketing companies helps to further the research, she further argues. To this day, she has been at odds with her entrepreneurial existence because of such accusations, which clearly wear her down. "I would have had an easier life without these companies," she rues. Then her forehead clears again, the unmistakable bright smile returns to her face:"But today I know that people live because Empatica builds these devices."

At the end of the conference, Picard is still surrounded by young researchers. She can hardly move, and her colleagues are waiting in vain for her to join them for dinner. "I can only encourage you," she says over and over again to the young people around her. "If you have an idea, work on it." "But what about the FDA? Do we have a chance?" asks a student. Many wearable computing developers are at war with the Food and Drug Administration which controls medical devices, because the FDA wants scientifically solid proof for statements like Picard's: "My device saves lives." But Picard's fighting for them: "At FDA there are some very smart people," she says. "They're open to ideas." One has to pay tribute to her, because she herself is struggling with the fact that such proof is hardly possible. "It's not possible to prove this causally," she says, and for the first time this day, she looks a bit downcast.

As long as the FDA does not approve her device as a medical product, it is merely an "expensive toy", as epilepsy specialist Loddenkemper puts it. He wants Picard to find a way to convince the FDA. "The data are so important," he says,"I don't want to get any more calls about a child dying during the night. Preventing that motivates me every day." The data could not only be used to predict the seizures of individual patients; it could also look for general patterns in the population, predict who will fall ill and which medications might help prevent that. But the only data available so far is based on patient self-disclosure. "They come to the doctor every few weeks, can't remember very well and sometimes don't even notice seizures themselves," says Loddenkemper. "Fifty percent of the data we have on epileptic seizures so far is false. What does that mean for drug studies? " he asks rhetorically, and answers his own question: "They contain mistakes because they are based on questionable data."

And then he makes it clear how much he believes in the causality he will never be able to prove: "We can't deny the device to anyone." Some time ago, some of his colleagues wanted to prove the effectiveness of parachutes against gravity. They published an article in *The Lancet*, "but they couldn't find a control group to try without the parachute." The whole thing was a joke, but Loddenkemper can't laugh. He doesn't even want to try to find a control group that doesn't use the bracelet. "That's not ethically correct," he insists. And Rosalind Picard doesn't have the heart to even finish this thought.