Medical Xpress

Education aids understanding, reduces stigma of facial paralysis, study shows

January 20 2015

A little bit of sensitivity training can help people form better first impressions of those with facial paralysis, reducing prejudices against people with a visible but often unrecognizable disability, new research from Oregon State University indicates.

There is a natural tendency to base first impressions on a person's face, but those impressions can be inaccurate and often negative when the person has facial paralysis, said Kathleen Bogart, an assistant professor of psychology in the College of Liberal Arts at Oregon State University.

"We wanted to see what we could do to change that, and we found that education is a powerful tool," said Bogart, who directs the Disability and Social Interaction Lab at OSU. "It takes away the uncertainty of how to accommodate the disability."

The research showed that providing education about conditions that cause facial paralysis helps people correct their misperceptions. Education efforts could be particularly beneficial to health care workers, educators or other groups that are more likely to regularly encounter someone with facial paralysis, Bogart said.

For example, understanding the need to pay attention to other modes of communication could help a doctor develop a better relationship with a patient and more accurately detect when the patient is upset or in pain. It also could help educators avoid the assumption that an unresponsive face means the student is not attentive, and to understand when a child is actually engaged in a task, she said.

Bogart is an expert on ableism, or prejudice about disabilities, and her research focuses on the psychosocial implications of facial movement disorders such as facial paralysis and Parkinson's disease, which affect more than 200,000 Americans. Her interest stems from personal experience; she has Moebius syndrome, a rare congenital neurological disorder characterized by facial paralysis and impaired lateral eye movement.

For the study, she conducted an experiment where some participants received sensitivity training in the form of educational information about facial paralysis, including the cause and nature of the disability. The information stressed the need to focus on body language and voice cues of people with facial paralysis. Other participants received no information on facial paralysis.

All 110 study participants were then asked to watch a series of video clips featuring people with facial paralysis, both mild and severe, and were asked to rate the sociability of the people in the videos. The people who read the educational information consistently rated people with facial paralysis as more sociable than those in the group that did not read the information.

"We found that awareness and education efforts are effective in reducing stigma related to rare disabilities such as facial paralysis," Bogart said. "That could have a broad impact on the rare disease community, because many rare diseases are unrecognizable. People who encounter someone with a rare disease may not understand or know how to adapt to communicate with them."

The findings are being published in the February issue of the journal "*Patient Education and Counseling*." Co-author is Linda Tickle-Degnen of Tufts University. The research was supported by a grant from the National Institutes of Health.

Bogart is now developing educational materials about Moebius syndrome targeted to educators and health care providers. She and the students in her lab also are conducting an awareness campaign in conjunction with Moebius Syndrome Awareness Day, which is held annually on Jan. 24.

The awareness campaign is a pilot project. Bogart and her students are encouraging people to take a self-portrait with a sign describing how they express themselves, then sharing the photos on social media sites using the hashtag #moebiusawareness. The Moebius Syndrome Foundation and several other college campuses are also participating in the campaign. For more information on the effort, visit: http://bit.ly/17BMR8o.

In the future, Bogart hopes to study the effectiveness of such educational efforts to determine if more information should be included, if other types of groups might be targeted or if there are other ways to enhance understanding of rare diseases such as facial paralysis.

Provided by Oregon State University

Citation: Education aids understanding, reduces stigma of facial paralysis, study shows (2015, January 20) retrieved 18 April 2024 from https://medicalxpress.com/news/2015-01-aids-stigma-facial-paralysis.html

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