Contrary to popular belief, ALS does affect the mind

September 12 2018

It's known as the disease that attacks the body but leaves the mind unaffected. But a new study shows that amyotrophic lateral sclerosis, also called ALS or Lou Gehrig's disease, does affect the mind, especially later in the disease. The study is published in the September 12, 2018, online issue of *Neurology*, the medical journal of the American Academy of Neurology.

ALS is a rare neurologic disease that mainly affects the nerve cells responsible for controlling voluntary muscle movement such as walking or talking. ALS is a disease that gets worse over time and eventually leads to death, most often from respiratory failure. There is currently no cure for ALS.

"Unfortunately, we found that people with ALS have problems with thinking skills as well as behavioral problems such as apathy, changes in eating behaviors and lack of inhibition even at the earliest stages of the disease," said study author Sharon Abrahams, Ph.D., of the University of Edinburgh in the United Kingdom. "By the last stage of the disease, only a small percentage of people are free of these cognitive and behavioral problems."

Abrahams said people with ALS should be routinely screened for these problems. "People with ALS and their caregivers should also be informed that changes in thinking skills and behavior can be a part of ALS so they can plan for and watch for these issues and know that they are related to the disease itself," she said.

The study involved 161 people with ALS who were compared to 80 people who did not have the disease. All of the participants took tests of thinking skills and the participants or their caregivers were asked about behavioral symptoms such as apathy and loss of sympathy or empathy.

The people with ALS were divided into groups based on what stage of the disease they were in, which is determined by how many regions of the body are involved in the disease. The regions are upper limbs; lower limbs; bulbar, which is the muscles affecting speech and swallowing; and breathing and eating. Stage 1 involves one region, stage 2 involves two regions, stage 3 involves three regions and stage 4 is when breathing or eating is affected enough that interventions such as breathing or feeding tubes are needed.

The people with ALS had worse scores than the control group on all of the thinking tests except visual-spatial ability, which is not known to be affected by ALS. Overall, 29 percent of the people with ALS had problems with their thinking skills, with the most common problems occurring on the test of verbal fluency, where people list as many items as they can that start with a certain letter, and the test of executive functioning, such as paying attention to two things at once.

Of the 149 people with ALS with information on behavioral symptoms, 45 percent had no problems, 22 percent had one symptom, 14 percent had two symptoms and 20 percent had three or more symptoms. Apathy was the most common symptom, at 31 percent, loss of sympathy or empathy affected 28 percent and changes in eating behaviors affected 25 percent.

The researchers also found that people had more problems with thinking skills and a greater number of behavioral symptoms at the more advanced stages of the disease. At stages 1 and 2, 20 and 21 percent had thinking problems, while at stage 3, 33 percent had problems, and 40

percent at stage 4. For behavioral problems, 18 percent were affected at stage 1, 27 percent at stage 2, 36 percent at stage 3 and 65 percent at stage 4.

Abrahams said that people whose disease affected their bulbar region were more likely to have problems with thinking skills and behavior than people whose disease did not affect that region, whether or not it was the first area of the body affected.

A limitation of the study is that it looked at participants at one point in time. Individual participants were not followed over time to see how thinking skills and behavioral issues changed as the disease progressed.

Provided by American Academy of Neurology