Muscular Dystrophy in the North Carolina Piedmont

Myotonic Dystrophy

What is Myotonic Dystrophy?

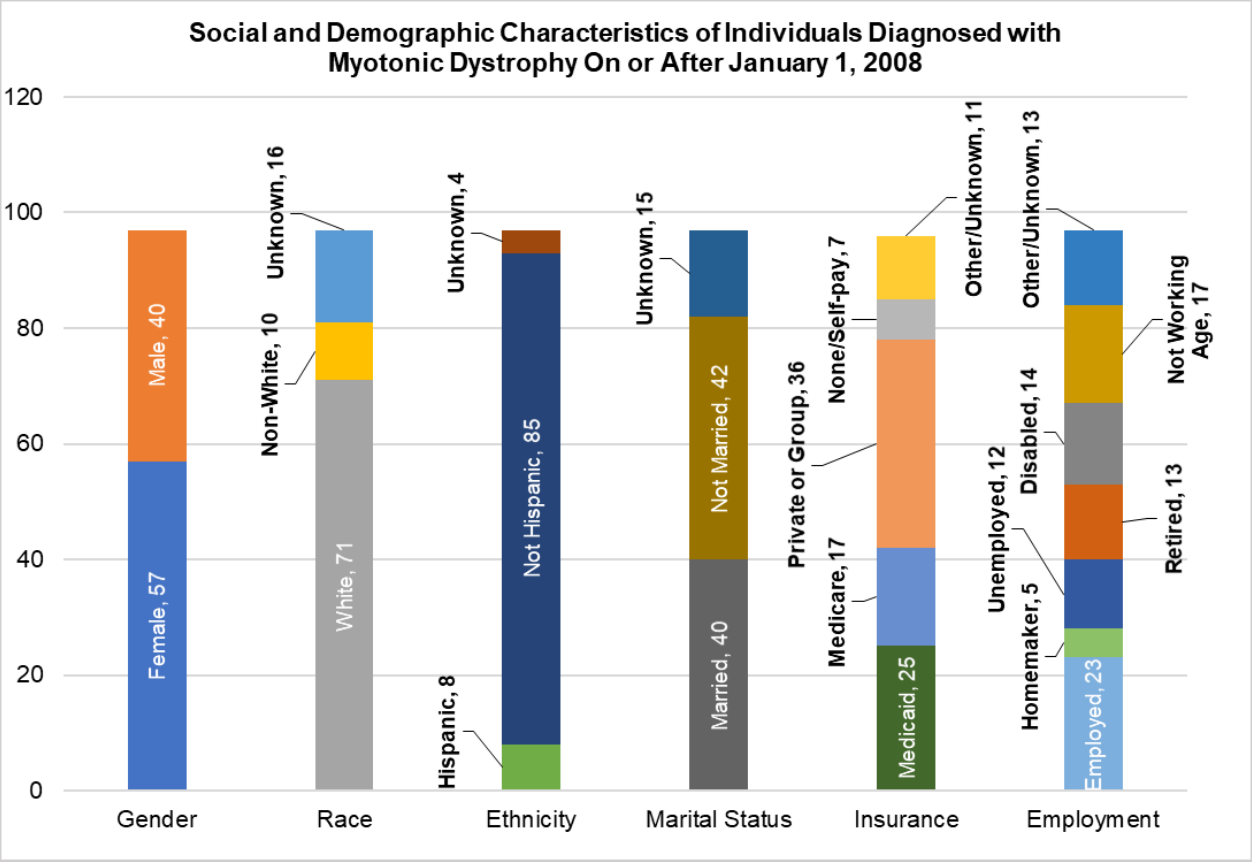
Myotonic dystrophy is a genetic disorder of muscle function. It is usually inherited from a parent with the disease. People with myotonic dystrophy have muscle weakness in their face, hands, or legs. They may not be able to relax their muscles after they contract. For example, they may be unable to let go after they grip an item. Individuals with the disease may also have breathing problems, abnormal heartbeat, or muscle pain. Signs of myotonic dystrophy usually first appear when a person is between ages 20 and 40, but signs can first appear at any age. There are two subtypes of myotonic dystrophy that are caused by different genes. Additional information about myotonic dystrophy can be found on the following websites:

Myotonic Dystrophy Foundation The Genetics Home Reference Muscular Dystrophy Association

Centers for Disease Control and Prevention

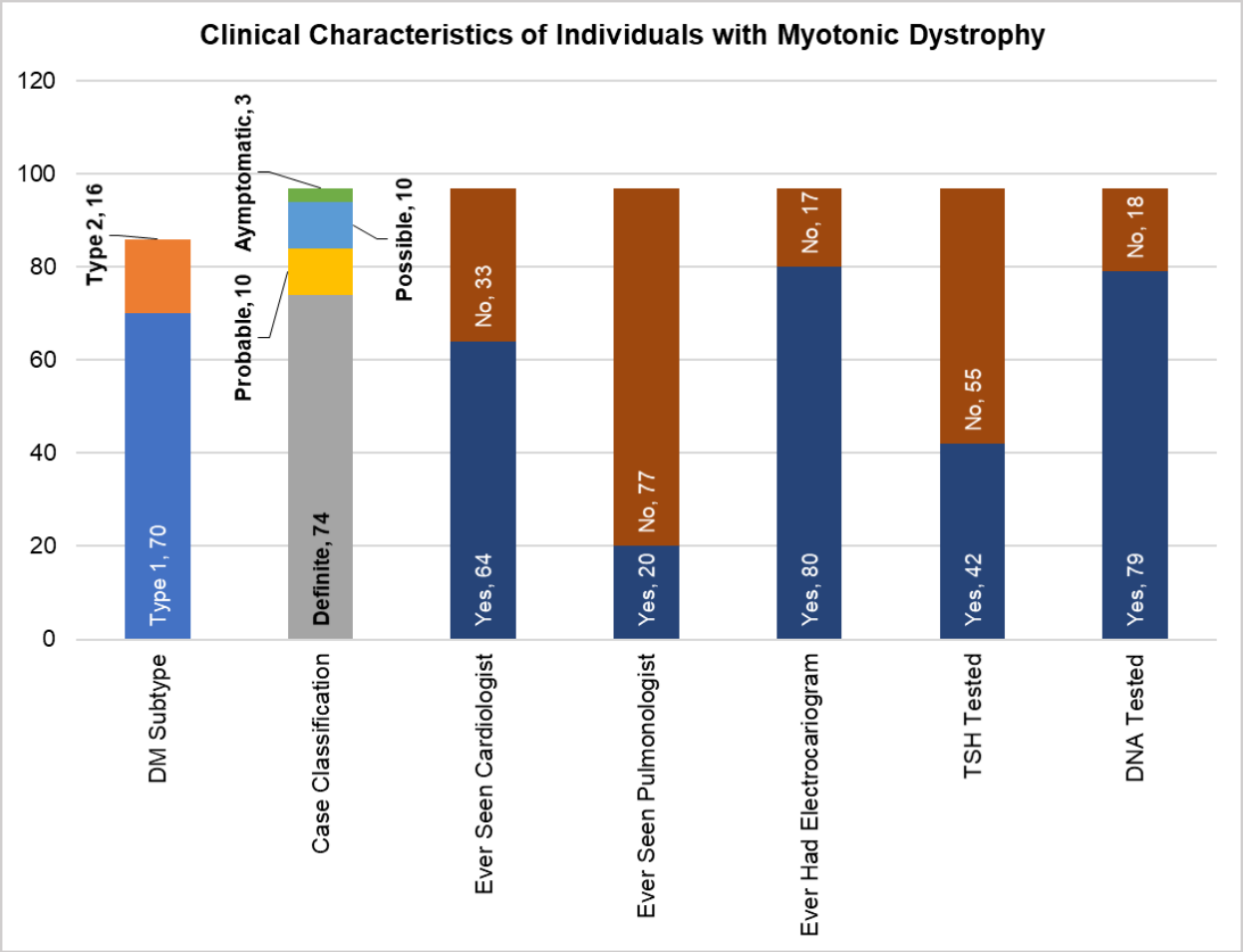
How Many People Have Myotonic Dystrophy in the Piedmont Region of North Carolina?

We identified 97 individuals within our study area who were diagnosed with myotonic dystrophy on or after January 1, 2008, and had a health care encounter between January 1, 2008, and December 31, 2016. On January 1, 2019, their average age was 45 years (standard deviation, 20.7 years). The following charts show the characteristics of people living with myotonic dystrophy In North Carolina. We study muscular dystrophy in 33 counties in the central region of North Carolina.



What Are Their Clinical Characteristics and What Clinical Care Have They Received?

Among the 97 diagnosed individuals we identified, 74 were confirmed to have myotonic dystrophy by genetic testing in themselves or a family member (definite), and 10 had clinical symptoms of myotonic dystrophy documented in the medical record (probable). Ten had a diagnosis of muscular dystrophy but without sufficient information to confirm the diagnosis (possible). Three had a positive genetic test but have not yet shown symptoms of the disease (asymptomatic). On average, people with myotonic dystrophy first showed symptoms of the disease at age 34 years and were first diagnosed at age 39 years.



How Did We Get These Numbers?

The Muscular Dystrophy Surveillance, Tracking, and Research Network (MD STARnet) is a public health surveillance program designed to collect health information on everyone with muscular dystrophies living in specific areas of the United States. MD STARnet identifies individuals with muscular dystrophy from medical records at neuromuscular clinics and other places they seek care. MD STARnet is funded and managed by the Centers for Disease Control and Prevention and comprises researchers at state departments of health, universities, and nonprofit research institutes. Each project is either reviewed and approved by Institutional Review Boards or authorized by the public health authority in the state in which the surveillance is conducted. North Carolina joined MD STARnet in 2014. We collect data about individuals with muscular dystrophies who live in any of the 33 counties in the central, Piedmont region of the state: Alamance, Anson, Cabarrus, Caswell, Chatham, Davidson, Davie, Durham, Forsyth, Franklin, Gaston, Granville, Guilford, Iredell, Lee, Lincoln, Mecklenburg, Montgomery, Moore, Orange, Person, Randolph, Richmond, Rockingham, Rowan, Stanly, Stokes, Surry, Union, Vance, Wake, Warren, and Yadkin Counties.

For more information on MD STAR*net*, see the CDC MD STAR*net* page. For more information about the North Carolina MD STAR*net* project, see our web page.