Communication with a disability of muscular dystrophy

Communication with a Disability of Muscular Dystrophy

Muscular dystrophy diseases cause weakness and degeneration of muscles. Many people know muscular dystrophy as a singular disease rather than a category of disease that contains group of diseases. There are multiple forms of Muscular Dystrophies (MD) such as Becker MD, congenital MD, Duchenne MD, limb-girdle MD, facioscapulohumeral MD, myotonic dystrophy, oculopharayngeal MD, and Emery-Dreifuss MD. The most common type of MD is Duchenne which is what will be discussed here. (Muscular Dystrophy Association, 2018)

French neurologist, Guillaume Benjamin Amand Duchenne, was the first to describe Duchenne muscular dystrophy (DMD) disease. DMD is an inherited disorder. It is much more common in boys than girls. The protein dystrophin has been identified as the one that is mutated which causes muscle cells to weaken. DMD can begin early and show signs at the age of three or four years. (Mayo Clinic, 2018) These signs can be delayed ability to sit, stand or walk and difficulty learning to speak. Usually, this disease starts affecting muscles in the pelvic area, upper legs and shoulder. Calf muscles start out enlarged with muscle tissue that is replaced with fat and connective tissues. A brace may be requiring for walking or a patient may be confined to a wheelchair by age of twelve. By early teenage years, the muscles of heart and respiration are also affected. “ Bones develop abnormally, causing skeletal deformities of the spine and other areas.” (National Human Genome Research Institute, 2013) In the past, the life expectancy with DMD patients was no more than their teenage years. However, with healthcare advances, the life expectancy is increasing and there are many survivors who have

stepped into their early thirties. There are also cases of men living in their fifties.

DMD is diagnosed in many ways. A clinical diagnosis is when a patient demonstrates progressive symmetrical muscle weakness before the age of five along with severely elevated creatine kinase blood levels. Genetic testing may be performed to see alteration or mutation in DMD gene which may be not conclusive. A muscle biopsy can be performed to check dystrophin levels. (National Human Genome Research Institute, 2013) There is no cure for muscular dystrophy. The current treatment helps with improvement on quality of remaining life.

According to Social Security Administration, muscular dystrophy is a disability characterized by “ disorganization of motor function in two extremities, resulting in an extreme limitation in the ability to stand up from a seated position, balance while standing or walking, or use the upper extremities” (Social Security Administrations, n. d., 11. 13) There is also marked limitation in physical and mentally capabilities.

The overall health for a patient with DMD can be quite severe especially when the heart and respiratory muscles are affected. These patients have been confined with wheelchair or brace and now they can’t breathe as their body is physically giving up. The lack of social life can be onset for many psychological conditions such as depression for many of these patients.

DMD can cause communication problem when the patient is unable to breath or when the muscles around face or mouth may be affected. There are increased risk for dyslexia, dyscalculia, and dysgraphia for children with

DMD. These children have trouble with short term verbal memory and that will impact the amount of information they are able to process in their brain at one time. Their attention span is little. Therefore, these children will understand part of the message and follow that only. They must be given information in smaller parts that introduces one new concept at a time. The research present today has been inconclusive in determining whether children with DMD have executive functioning problem. (Poysky, Axelrad, Bonin, & Hendriksen, 2011)

To accommodate DMD patient, we, as health care workers, must use simple language with short sentences to make sure that they are able to follow the instructions. If an interventional procedure is required, having a visual aid may help and alleviate the fears. We must be extra calm and patient and try not to rush a procedure even if our schedule is compact. It would be a good practice to have the patient repeat instructions or procedure’s next step to make sure that the patient can be cooperative for the procedure by having clear understandings.

For the following scenario, John Smith, twelve year old, DMD patient is undergoing MRI brain with and without contrast. As a pre-confirmation appointment phone call to parents, there is no allergy to any food, contrast or drugs for this patient. On the day of the appointment, parents have arrived with the patient and have checked into the department, waiting for their turn. A technologist approaches patient and introduces herself to the patient and family and brings them into Zone 2 for MRI screening. A technologist has used family as the the one with reliable source of information but the technologist was prepared to show a video of how IV is

started and how allergic reactions can be. Technologist uses phrases such as “ machine is very loud,” “ don’t move,” “ there is going to be line connecting to your hand,” and “ the liquid will go in your body from that line.” Technologist would make sure patient explains the procedure back to her. The best approach for allergic or medical history after the parents would be to just casually talk to patient and ask like did you ever have this exam done before? Or do you like nuts? After making sure the patient is ready, the patient would be helped positioning inside the machine and perform the scan carefully.

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