

Management of Duchenne Muscular Dystrophy (DMD) via Telemedicine: *Continuity of Care for an Existing Patient*



Patient Characteristics and History

- 11-year-old male
- Diagnosed with DMD at age 3
- Ambulatory, but no longer able to rise from the floor or navigate stairs

Background

- The patient was an existing clinic patient
- The family was inexperienced with the use of telemedicine before the COVID-19 pandemic
- Routine multidisciplinary visits continued every 6 months, even during the pandemic
- The family had concerns with coming into the office during the pandemic
 - o Challenges with mask compliance
 - o Travel distance to the clinic



Telemedicine in Practice

Family Preparation for the Visit

- The clinic staff provided instructions for Zoom download and usage
- The family was encouraged to use a portable device for flexibility when performing functional assessments
- The clinic staff recommended that the child wear clothing with enhanced visibility (eg, shorts)

Outcome

- The family was satisfied with the quality of care delivered through telemedicine
- The patient was scheduled for an in-person multidisciplinary visit in 6 months



Advantages to telemedicine use

- Observation of a patient in his home environment
- Potential for more open and talkative patients
- More convenient for nonambulatory and ventilator-dependent patients
- Potential rotation with in-person visits to reduce the burden of patient transport and exposure to illnesses



Challenges to telemedicine use

- Difficult to assess certain time function tests
- Unable to perform a PFT remotely
 - o Must be performed in person and may require a COVID-19 test
- Less compliance with lab test appointments
- Coordination of multidisciplinary care potentially challenging
- Difficult to measure height and weight accurately for monitoring drug side effects

“Seeing a patient [with DMD] over a telemedicine appointment is better than not seeing a patient at all.”

- Debra Guntrum, MS, FNP
Nurse Practitioner,
Neuromuscular Disease Center

Some Practices With Telemedicine



Patients can be observed

- Stretching
- Rising and transferring from various surfaces in their home
- Using their equipment



Caregivers can talk through assessments, monitor for contractures, and assess sensation



PT assessments can be performed, including

- NSAA
- Brooke scale
- Vignos scale