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Duchenne Muscular Dystrophy- How to (Or Not to) Return to School?

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Abstract

The outbreak of coronavirus disease (COVID-19) is a Public Health Emergency of International Concern. While COVID-19 continues to spread, the protection of children and educational facilities is of prime importance. Limited data suggests children are low risk and get less severe COVID-19 infection. However, there is an increasing concern that patients with Duchenne and Becker Muscular Dystrophy (DBMD) may be at increased risk of developing multisystemic and severe complications of COVID-19 due to major comorbidities. As school and health care authorities prepare to open in person schooling this fall, the parents and caregivers of children with DBMD face new and challenging decisions about how their child will return to school this fall. When deciding between in-person and virtual learning, limited data is available for parents and health care providers to make this decision for children with DBMD. Here we will review some important considerations that can help make the best-informed decision for this special population.

Keywords: Duchenne and Becker Muscular Dystrophy; COVID-19 Virtual learning

Short Communication

Since the first case of Corona Virus Disease 2019 (COVID-19) was reported in Wuhan, China on December 8, 2019, the Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2) has spread rapidly throughout the world. While children have been less affected by COVID-19 compared to adults, children with certain medical conditions may be at increased risk for severe illness [1]. Children who are medically complex, who have serious genetic, neurologic, metabolic disorders, and with congenital heart disease might be at increased risk for severe illness from COVID-19. One CDC report noted that the majority of hospitalized children with COVID-19 in the United States had one or more underlying medical conditions such as chronic lung disease, cardiovascular disease, and immunosuppression [2]. There is an increasing concern that patients with Duchenne and Becker muscular dystrophy may be at increased risk of developing multisystemic and severe complications of COVID-19 due to major comorbidities such as chronic immunosuppression from corticosteroids, respiratory insufficiency leading to poor airway clearance and the need for long-term ventilatory support, and cardiac dysfunction [3]. In response to the COVID-19 pandemic, almost 200 countries had implemented country-wide school closures [4]. This kept multiple children, including those with complex medical conditions including DBMD at home and allowed to maintain social distancing. However how helpful this is to reduce transmission of COVID-19 has been debatable. Clear evidence to suggest that school closure contribute to the control of the epidemic is lacking. Recent studies of COVID-19 predict that school closures alone would prevent only 2-4% of deaths, much less than other social distancing interventions. Studies from the SARS outbreak in mainland China, Hong Kong, and Singapore suggest that school transmission played no substantial role in the outbreak, and that school closures and other activities such as school temperature monitoring did not contribute to control of infection transmission [6-8].

In the current times both, the Center for Disease Control (CDC) and the American Academy of Pediatrics (AAP), are recommending re-opening of school in the United States. According to the CDC, as of July 17, 2020, the United States reported that children and adolescents under 18 years old account for under 7 percent of COVID-19 cases and less than 0.1 percent of COVID-19-related

deaths [9]. Studies suggest that COVID-19 transmission among children in schools may be low. International studies, where schools have re-opened, have assessed how readily COVID-19 spreads in schools. They are reporting low rates of transmission when the community transmission is low. Current data from these also shows the rate of infection among younger school children, and from students to teachers, has been low, especially if proper precautions are followed. There have also been few reports of children being the primary source of COVID-19 transmission among family members [10-12]. This is consistent with data from both virus and antibody testing, suggesting that children are not the primary drivers of COVID-19 spread in schools or in the community [13-15]. The results are still not conclusive, but the available evidence points to the theory that in-person schooling is in the best interest of students, particularly in the context of appropriate mitigation measures being implemented. This low presumed risk for children is countered by the potential harm prolonged school closure may cause in the long term. It can lead to significant learning loss, particularly in students with heightened behavioral and special needs for whom in-person instruction is vital [16,17]. Of another particular concern is the disparities in educational outcomes caused by school closures for low-income and minority students and students with disabilities [16].

What does this mean for children with DBMD and their families? Parents, caregivers, and guardians of children with DBMD face new and challenging decisions about how their child will return to school this fall, such as deciding between in-person and virtual learning. As mentioned above, limited data about COVID-19 in children suggest that children are less likely to get COVID-19 than adults, and when they do get COVID-19, they generally have less serious illness than adults. However, it is clearly identified that children who are medically complex, who have neurologic, genetic, metabolic conditions, or who have congenital heart disease might be at increased risk for severe illness from COVID-19, compared to other children. Severe illness means that they may require hospitalization, intensive care, or a ventilator to help them breathe, or may even die [2]. Children with DBMD often will qualify for more than one of the listed risk factors due to use of corticosteroids, being non ambulatory, respiratory weakness/insufficiency, cardiac insufficiency, intellectual disability, and mental health/behavioral disorders. CDC has provided a 'Decision making' tool for parents to try to make a calculated decision about in person versus distance learning for their child [18-20]. The questions in these tools are designed to help you weigh the risks and benefits of available educational options before you make decisions. This tool is a general tool and may not apply to children who are high risk like the DBMD patients a hundred percent. Some of the questions listed below may be helpful for families to try to come to an informed decision.

a. Does my child have an underlying condition that increases the risk for severe illness from COVID-19? Children with DBMD not on steroids, with no cardiac or respiratory symptoms would not be considered very high risk based on the known literature. Prolonged use of corticosteroids however might increase the risk for more severe COVID-19 infection. The recommendations however are to continue steroid therapy with stress dosing if sick. Any cardiac involvement or respiratory compromise puts DBMD patients in higher risk for severe infection.

b. Do I live with someone, or my child's caregiver, is at increased risk for severe illness from COVID-19 due to age or underlying medical conditions? If the DBMD child is not high risk based on CDC criteria (19), but their caregivers/family members are at high risk due to an underlying co-morbidity, it might be a consideration for avoiding in person school.

c. Is the level of community spread in my area is high? A critical role in successful opening of schools depends on the local infection rate in the community. According to the UNMC Public health department and biocontainment center, success of the 15 countries internationally in reopening in person schools was because they waited until transmission rates were less than 10 cases/million population/day (20). Risk assessment for timing to return to in person schooling will also factor in the local health authority's preparedness with testing, timely contact tracing and quarantine. The best protection to children, teachers, and staff from getting COVID-19 infection is reducing the community transmission rates.

d. Do I know my school's plan for COVID preparedness, and do I feel comfortable with it? Review your local school or school district reopening plans to understand the steps they are taking to reduce the spread of COVID-19 and support educational goals. Know how your school is planning to implement social distancing, hand washing, mask wearing, frequent disinfection and proper ventilation. Consider if your child will be able to follow the guidelines.

e. Does the school have plans for taking care of children with special needs? If the school nurse gets sick, know if there is there a backup plan, especially if your DBMD child needs any medication or medical care during school hours. If a child needs an aid, ensure that proper screening/testing and social distancing can be maintained.

f. Is my child's mode of transportation to and from school safe? If your child is using the public transportation, know what measures are being taken for reducing the risk of spreading COVID-19. Some proposed measures may be decreased bus/transit capacity, mandatory wearing masks, increased cleaning, and disinfecting practices. Be informed about how they will accommodate these measures for children in wheelchairs or other special equipment.

g. Is Virtual/At-Home Learning Feasible for my child and our family? To assess if virtual learning will be feasible for your home environment is crucial to make sure your child will succeed in home learning. Ensure that you or someone you have identified will be able to supervise virtual learning. Another aspect to consider would be the learning style and needs of your

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child, would they be compatible with distance learning. Access to reliable internet and digital device for your child to use would also be needed.

h. Does my child receive school-based services? If your child received school-based services like physical therapy, occupational therapy, speech therapy or mental health services, will you still be able to receive these services virtually or have an at home option. If your school only provides on site services and your DBMD child is high risk, address these concerns with your school. A major proportion of children with DBMD have an individualized education plan, specialized classes, or extra tutoring. Assessing if your child will have access to these services virtually/at home and will they meet your child's needs adequately is a critical factor to ensure your child thrives in their academic and social goals.

In conclusion, choosing whether or not to send your child back to school during the COVID-19 pandemic can be a very difficult decision for parents of children with DBMD. The safety data for children returning to school is extremely scarce. The health organizations and local school districts are making best efforts to try to evaluate the situation and plan a safe return to school for a large population of school aged children. These measures are however mostly tailored for children who are presumed to be low risk in general. The CDC has identified children at high risk, but no clear guidelines are available for these families or schools on how to make their return to school safe. When weighing decisions about your child returning to school, it is important to consider your child's/family's unique needs, your school's ability to accommodate these virtually/at homes, and the situation of the pandemic in your community. Consulting with your health-care providers, local health care authorities and school representatives regarding your concerns, special considerations or safety measures pertaining to the COVID-19 risk mitigation should also be a vital part of your decision making..

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