

Retrospective chart review of fat embolism syndrome in Duchenne Muscular Dystrophy

Project Summary

Centre for Leadership in Child Development

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RESEARCH INSTITUTE

SHARING OUR WORK

- We will develop an education pamphlet about Fat Embolism Syndrome in Duchenne Muscular Dystrophy, to be shared with families, clients, schools and pediatricians.
- Publication in a medical journal to share the findings of the chart review

WHAT WAS THIS STUDY ABOUT?

The purpose of this study was to describe the presentation and clinical course (how a disease behaves over time) of Fat Embolism Syndrome (FES) and its long term after effects in Holland Bloorview clients with Duchenne Muscular Dystrophy (DMD).

WHAT DID WE DO?

- We did a chart review of Holland Bloorview clients with DMD who developed FES after a traumatic injury such as a fall or fracture. The review was over a 15 year period from 2000 to 2015.
- The clinical course noted whether clients showed physical or cognitive differences after the occurrence of FES. In some cases, the clients did not survive the onset of FES. In those instances, the clinical course was described from the time of trauma until the time of death.
- We analyzed the data for differences in presentation and clinical course comparing those who survived to those who did not.
- Additionally, a review of the literature was performed to integrate knowledge of Fat Embolism Syndrome in DMD.

IMPACT FOR CLIENTS, FAMILIES AND CLINICAL PRACTICE

FES is discussed with families and individuals with DMD, however, there is limited clinical information available. Our goal is prevention of FES through safety awareness and early identification through education.

The pamphlet provides families with detailed information about the presentation and clinical course of FES in DMD. The pamphlet will also assist doctors in recognizing FES in DMD.

WHAT DID WE LEARN?

- Prevention of injury is important.
- There is no clear clinical predictor of death in the different presentations of FES.
- All cases had respiratory distress as the presenting symptom.
- The majority of cases had neurologic symptoms caused by, or occurring in, the nervous system. These symptoms could have been directly related to a trauma. A few clients in the review had developed petechia (pinpoint, round spots that appear on the skin as a result of bleeding).

NEXT STEPS?

We are continuing work on a paper which will be submitted for publication.

The paper as well as a factsheet will be shared with clients and families. Copies will be provided to health care providers and teacher/special needs educators in schools who have students with DMD; as well as Muscular Dystrophy Canada.

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WHO ARE WE?

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