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Case Study: Monitoring Sleeping Patterns of a Boy with Duchenne Muscular Dystrophy and his Caregivers

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Duchenne Muscular Dystrophy (DMD) is a terminal disease involving a progressive degeneration of muscle and motor function in young males, which impacts the entire household. Families exposed to these DMD management demands can be overwhelmed, resulting in sleep disruptions. This current study was implemented to investigate relationships in sleep patterns among boys with DMD and their caregivers. **PURPOSE**: Based on initial data, we present a case study exploring quantitative and qualitative sleep patterns of a young boy with DMD and his parents. **METHODS**: A 10y ambulatory boy with DMD and his parents wore a portable fitness tracking device (PFTD) for one month. The PFTD monitored and recorded sleep efficiency (SE) and amount of nocturnal wake-ups (NWU). A proxy-reported Children's Sleep Habits Questionnaire (CSHQ) was used to evaluate child sleep disturbances. Pearson correlation and paired sample t-tests (SPSS 21.0; SPSS, Chicago, IL) were used to identify relationships and differences, respectively. Statistical significance was set at $p < 0.05$ and results were reported as mean ± SD. **RESULTS**: Relationships between PFTD SE and NWU existed for the father (SE = 93.5 ± 0.6% vs. NWU = 3.8 ± 0.3; r = -.640), mother (SE = 91.9 ± 1.0% vs. NWU = 8.6 ± 0.5; r = -.867), and their son with DMD (SE = 83.7 ± 1.1% vs. NWU = 8.6 ± 0.5; r = -.436). Based on PFTD, parents higher SE and lower NWU were significantly different from their son with DMD (p = .000). SE for the boy with DMD was inversely related to CSHQ morning wake-up times (r = -.986), and tended to be improved by moving to someone else's bed during night (r = .942, p = .058). Also, falling asleep in brothers or parents bed instead of alone (p = .023) tended to reduce NWU experienced by the son with DMD (r = -.870, p = .130). PFTD data and CSHQ scores demonstrated general caregiver awareness of son with DMD NWU more than once during the night (r = .905, p = .095). **CONCLUSIONS**: Although sleep patterns were similar for all three family members, the 10y boy with DMD showed lower SE and more frequent NWU compared to his parents. Further research is warranted to investigate relationships in sleep patterns among a larger dataset of boys with DMD and their caregivers. Identifying sleep habits and patterns can be beneficial to determine strategies that will reduce NWU and improve SE for boys with DMD as well as the whole family.

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