

Title

Clinical features of those using powered indoor/outdoor wheelchairs (EPIOCs) with a muscular dystrophy: disease features, comorbidities and complications of disability.

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Abstract

Objective To describe the clinical features of EPIOC users with a muscular dystrophy (MD) and explore the complexities of comorbidities, clinical features and conditions secondary to disability influencing prescription.

Method Cross-sectional survey of a clinic population. Records were reviewed by a consultant in rehabilitation medicine, data systematically extracted and entered into a database. Further data were entered from clinical records. Data were extracted under three themes; demographic, diagnostic and clinical profiles and wheelchair factors.

Results Sixty five users (mean age 23.7, range 10-67, sd 12.95 years) had a diagnosis of a MD and 39 had additional clinical features (ACFs). Fifty-one were men (mean age 22.6, range 10-67, sd 12.9 years) and 14 women (mean age 27.7, range 10-49, sd 12.9 years). The majority had Duchenne MD (n=40). ACFs influencing prescription were scoliosis (n=20), problematic pain (n=14), ventilatory failure (n=4), pressure sores (n=2), dependent oedema/cellulitis (n=2).

Tilt-in-space (TIS) was provided to 48 users and specialised seating (SS) to 35 (30 having both SS and TIS). Complex controls were provided to 17 users including tray mounted (n=14), non-standard (n=7) and interfacing issues (n=6). Bespoke seating was provided to 12 users: carved foam (n=4), Scott systems (n=4), Matrix (n=3) and moulded seat insert (n=1). Pressure relieving cushions prescribed were Jay 2 (n=14), Qbitus (n=10), Vicaire (n=4), RoHo (n=3) and other (n=9). Thirteen had standard cushions.

Conclusion

Management of posture is critical in MD and is complicated by growth and disease progression. Complex, individually tailored, EPIOC prescription requires clinical expertise from experienced multidisciplinary teams.

Topic Areas

- Seating and Positioning
- Mobility
- User Needs

Keywords

muscular dystrophy, powered mobility, comorbidity

Conclusion (paper and poster presentations only)

Management of posture is critical in MD and is complicated by growth and disease progression. Complex, individually tailored, EPIOC prescription requires clinical expertise from experienced multidisciplinary teams. Distinguishing between features of the disease, comorbidity and complications of disability is complicated. Complexity of the clinical assessment may best be considered by adding these factors together, as 'additional clinical features'.

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