Patient Preferences for Treatments of Neuromuscular Diseases: A Systematic Literature Review.

Landfeldt E, Edström J, Lindgren P, Lochmüller H.

Abstract

BACKGROUND: Treatment decisions of neuromuscular diseases involve weighing clinical benefits and risks, as well as impact on patient social life, work status, other activities of daily living, and health-related quality of life.

OBJECTIVE: To conduct a systemic literature review of patient preferences for treatments of neuromuscular diseases.

METHODS: We searched Embase, Web of Science, and PubMed for full-text articles reporting results from studies of patient preferences for treatments of neuromuscular diseases. We excluded articles published before the year 2000, articles written in a language other than English, articles only reporting proxy-assessments of patient preferences, and studies reporting results for a sample comprising <5 patients.

RESULTS: The search resulted in the identification of 305 unique publications. Of these, 275 were excluded following title and abstract screening and 23 following full-text review. Seven articles were included for data synthesis. Preference data were identified for a hypothetical treatment with pulmonary benefits of Duchenne muscular dystrophy and Becker muscular dystrophy, pathways for different routes of opioid drug administration in motor neuron disease, wheelchair features in amyotrophic lateral sclerosis (ALS), ankle foot orthoses in patients with Charcot Marie Tooth disease, and mechanical ventilation in ALS and a mixed cohort of patients with neuromuscular diseases.

CONCLUSIONS: Despite considerable research into the development of new health technologies targeting neuromuscular diseases, little is known of patients' preferences for pharmacological interventions. More research is needed to help incorporate patient preferences in clinical decision-making to improve treatment satisfaction, medication compliance, and health outcomes.
KEYWORDS: Neuromuscular diseases; decision making; health policy; patient preference; patient-centered medicine

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