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Use of the Assessment of Caregiver Experience with Neuromuscular Disease (ACEND) in Spinal Muscular Atrophy

Background

Spinal muscular atrophy (SMA) has a remarkable impact on function and participation. Subsequently, the caregivers of individuals with SMA are impacted as well. Providers and the SMA community should be aware of the presence of and likely expectations for the existence of caregiver burden.

Methods

The Assessment of Caregiver Experience with Neuromuscular Disease (ACEND) quantifies caregivers' perceptions of function and quality of life pertaining to time, finance and emotion. Analyses were conducted among SMA types and ambulatory and ventilatory status. Participants with SMA had varying ranges of function and were on pharmaceutical treatment. Total ACEND score, longitudinal change in total ACEND score, total quality of life (QOL) score, change in total QOL score and subdomains for QOL, including time, emotion and finance, were all explored.

Results

Overall, the ACEND demonstrated discriminant validity and some observed trends. Total ACEND scores improved for caregivers of those with SMA 2, remained stable longitudinally for caregivers of those with SMA 1 and 3 and were not influenced by ventilation status. The caregivers of individuals with SMA 1 had the lowest total quality of life (QOL) score, as did the caregivers of non-ambulatory individuals and those requiring assisted ventilation. Longitudinally, there were no changes in total QOL between caregivers of individuals with different SMA types or ambulatory or ventilation status. There were some differences in emotional needs, but no differences in financial impact between the caregivers of individuals with different types of SMA or ambulatory and ventilatory status.

Conclusions

With this information enlightening the presence of caregiver burden and expected changes in burden with pharmaceutical treatment, providers, third party payors and the SMA community at large can better assist, equip and empower those providing the necessary assistance to enable the lives of those with SMA.

Keywords: ACEND; caregiver burden; neuromuscular; pediatric; quality of life; spinal muscular atrophy

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Biography

Laurey received her doctorate in physical therapy from Washington University in St. Louis. Afterward, she completed a Leadership Education in Neurodevelopmental and Related Disabilities fellowship at the Institute for Inclusion in Boston, MA. She has worked as a physical therapist at the Reichman University for the past 15 years, where she primarily cares for children with musculoskeletal, neuromuscular, and developmental conditions. She also has served as a clinical evaluator for neuromuscular clinical trials.

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