Identifying Care Coordination Barriers and Optimal Support Practices for Families of Patients with Lysosomal Storage Disorders

Abstract P528

Introduction: Lysosomal Storage Disorders (LSDs) are individually rare and progressive multi-system conditions often resulting in early mortality. Caregivers often face high coordination burden following their child's diagnosis, which conflicts with existing resource-intensive socioeconomic challenges for some families. The problem lies in limited follow-up support in their child's care management, with under-monitoring presenting risk to a child's health status and quality of life. In this quality improvement project, we aim to characterize and improve caregiver capacity, capability and engagement in their child's healthcare needs, to enhance health equity and set a basis for holistic continuity of care.

Methods: Patients with a confirmed or suspected LSD diagnosis by labs and genetic testing were included. Caregivers were contacted 1 week and 1 month post Genetics and Metabolism visit, addressing a) immediate health concerns, b) social support needs, c) healthcare education needs, and d) post-encounter Action Items (AIs). Healthcare barriers were surveyed at 1 month. A modified Post Encounter Action Grid message was sent via Electronic Health Record (EHR) portal, and support was later given to bridge caregiver access.

Results: Approximately half (51%) of caregivers face at least one barrier to meeting healthcare needs. When multiple pre-categorized barriers were assessed per family, the most frequent were conflicting obligations, healthcare cost, complex urban/healthcare environments, and transportation. When the top barrier was assessed per family, the most frequent were conflicting obligations, patient/family illness, childcare needs, and knowledge of upcoming visits. Overall caregiver engagement, as defined by at least one phone contact or EHR message read, increased by 14%. A majority (80%) read the Post-Encounter Action Grid message, and 89% found it useful for coordinating care. There was a 10% increase in EHR portal access, and a 26% increase in AIs completed at 18 weeks prior vs. 18 weeks following care coordinator engagement. Notably, 12 caregivers (17%) had no-show rates of ≥20% regardless of primary language. The majority were Mucopolysaccharidosis and Nieman-Pick Disease families, some of whom facing up to 10 AIs.

Conclusion: Caregiver capacity is limited by conflicting obligations and childcare needs, and capability limited by way of coordination skills, healthcare and tech education, and financial and logistical support needs. High care coordinator engagement showed improvements in caregiver healthcare engagement and the completion of AIs for their child(ren), reducing gaps to standard of care. Future PDSA cycles will further integrate sustainable provider based, caregiver empowering coordination methods.

Category:
Health Services and Implementation