



Children and Youth with Special Health
Care Needs National Research Network

Research Project Brief

PROJECT | Assessing Confidence at Times of Increased Vulnerability (ACTIV – Phase 1)

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Background | Caregivers of children with medical complexity (CMC) may be able to accurately and efficiently evaluate clinically meaningful changes in their child's health. Single-center studies have observed that parents' lack of confidence in their child's health has correlated with their child's risk of readmission shortly after discharge. If caregiver confidence can be clinically monitored longitudinally in real time, then potential exists not only to link it with downstream health outcomes, but also to target timely interventions to help caregivers at high-risk moments. This pilot study evaluated (1) feasibility and acceptability of an innovative health information technology to collect repeated measures of caregiver confidence of their CMC's health over time when implemented within a complex care program; and (2) viability of constructing trajectories of caregiver confidence in CMC's health and relationships among confidence, hospital utilization, and child and caregiver health-related quality of life.

Results identified significant associations between low confidence and hospitalization. When caregiver confidence was low, CMC had over three times higher odds of being hospitalized in the next 2 weeks compared to when confidence was higher. Mixed-methods data suggested texting was feasible and acceptable, implying the potential for refined versions of the platform to be integrated into real-time monitoring and clinical response systems.

Potential Impact | A hallmark of medical complexity is unpredictable and severe illness exacerbations often necessitating hospital care. Health crises for children with medical complexity (CMC) typically emerge at home, where families are first in line to manage nuanced, frightening, and technically challenging episodes. At times of acute illness, CMC care routines can be especially difficult. Clinical programs often have a limited ability to proactively identify and support families in the earliest moments that caregiver concerns arise. Given the observed associations between caregiver confidence and future hospitalization, this platform may ultimately prove effective at triggering just-in-time adaptive interventions to support vulnerable periods and improve key child and family health outcomes, including hospital utilization.



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