Meeting the Needs of Children with Complex Medical Needs in a Changing Health Care System

Statement of Problem

Children with complex chronic conditions like congenital heart diseases, congenital anomalies, cystic fibrosis, and cancer represent about 7% of all children, but are responsible for 40% of all pediatric costs. These children and their families often navigate multiple health care providers and are consistently at high-risk for emergency department visits and hospitalizations. Many families have very limited options for health care providers and, for some, the nation's children's hospitals are the only place their children can receive specialty care. As health care reform policy debates continue in our country, delivering higher-quality care coordination and improving the quality of life for families of children with complex chronic conditions will be a paramount goal. We must also be attentive to the fact that health insurance reform could introduce potential challenges for families, many of whom are already facing steep out-of-pocket costs for care and limited and timely access to appropriate providers.

Compounding the barriers families experience to receiving adequate, affordable health care is the fact that health care systems are facing growing challenges around capacity management, patient access and patient engagement. For families, this has led to longer wait times for appointments, less individual time with providers, and the difficult task of coordinating multiple appointments and follow-up recommendations among various specialists for children with complex medical conditions.

Description

In response to these challenges, Children's Hospital of Philadelphia's (CHOP) Population Health Innovation team is working to develop and implement programs of tailored population management tools and proactive patient outreach strategies for families of children with complex medical conditions. When goals overlap, the implementation work of the Population Health Innovation team is informed by PolicyLab research and engages PolicyLab content experts. The Population Health Innovation team works with care teams around the health system as they manage patients with complex chronic conditions such as diabetes, asthma, sickle cell disease, and inflammatory bowel disease, as well as various multidisciplinary clinics and a large wellness management program in primary care. The team employs quality improvement methodologies and tools to redesign clinical care team workflows, build and implement electronic health record (EHR)-based proactive care management tools (such as registries, real-time patient management reports and risk scores), and track longitudinal process and outcome measures to ensure that the clinical programs are meeting their care delivery goals.

As the Population Health Innovation team implements new programs throughout the health system and within the community, our teams at PolicyLab have worked with CHOP care teams to develop strong quality improvement designs, as well as robust mixed-methods and quantitative evaluations of the programs' impact. For example, a multidisciplinary working group led by PolicyLab researchers and the Population Health Innovation team worked with asthma care teams to implement and evaluate a multi-faceted population health

approach to keeping youth with asthma out of the hospital. The bundle of integrated services these children received included personalized bedside asthma education, facilitated filling of discharge medications, and connection to community health workers who could facilitate enhanced coordination between inpatient and outpatient care teams. Through the evaluation, we demonstrated a sustained reduction in repeat emergency department visits and hospital readmissions among the highest-risk asthmatic patients.

From the early development of care management programs, to the Population Health Innovation team's high-risk asthma initiatives, to the implementation and adoption of targeted population health management strategies and tools by primary care and specialty care teams, our researchers have demonstrated consistent and reproducible reductions in acute service utilization by patients with complex medical conditions.

Next Steps

Standardizing the work of clinical care teams with quality improvement methods and integrated EHR tools can provide a scalable strategy for health systems to address issues of capacity management, patient access and patient engagement. By providing leadership in the development of new population approaches to care coordination for children, the Population Health Innovation team works to provide a templated design, implementation, and evaluation process for other clinical care teams at CHOP that seek similar ventures to improve population management through improved patient access and engagement. Increasingly, these programs are creating stronger relationships with community service agencies that can assist people outside of the hospital setting, too. These broader initiatives will be the focus of implementation and evaluation studies in the years to come.

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