

# Study takes first steps to improve the quality of health care for chronically ill children

November 16 2010

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Children with chronic health conditions such as cystic fibrosis, type 1 diabetes, sickle cell diseases and cerebral palsy represent less than two percent of the population but can consume more than 50 percent of resources at children's hospitals throughout the country. Coordinating care for these children has historically been difficult because hospitals have varying methods to identify them in their systems. In a new study led by John Neff, MD, of Seattle Children's Research Institute, researchers developed a unique method to identify children with serious lifelong chronic conditions using hospital discharge data that will enable children's hospitals to improve the quality of care for these patients and reduce costs. The study, "Identifying Children with Lifelong Chronic Conditions for Care Coordination Using Hospital Discharge Data," published online November 15 in *Academic Pediatrics*.

"In the long run, if we can identify these [children](#), their cost patterns and needs, hospitals can then work with the state and health plans to provide support for the care coordination that they need. This should result in better quality of care and hopefully lower costs for these children," said Dr. Neff, clinical director at The Center for Children with Special Needs at Seattle Children's Hospital.

"One of the big barriers in the past is that hospitals have not known who their patient population is and have not been able to systematically identify them," added Neff. "Categorizing children with complex or multiple [chronic conditions](#) is particularly difficult because of the general infrequency and variable nature of their conditions. Because

hospitals haven't had a reliable method to identify these [patients](#), they haven't been able to effectively coordinate their care or know the cost implications to their own hospital."

Findings suggest that children with lifelong chronic conditions require a disproportionate share of resources in children's hospitals and when measured over several years are likely to accrue a high percentage of health costs. The study reviewed one hospital's records from 2007; these children represented 41.1 percent of Seattle Children's Hospital total patients and 71.4 percent of patient days.

Neff and co-investigators combined the use of [hospital discharge](#) data from Seattle Children's Hospital and its primary care clinic, Odessa Brown Children's Clinic (OBCC) over seven years from 2001 through 2007. They selected patients whose primary care occurred at OBCC and hospitalization and emergency department care were likely to be at Children's. Using Clinical Risk Groups (CRGs) software to analyze the data - CRGs is a risk adjustment method that has been used with health plan data to identify and stratify individuals into condition and severity groups, but has not previously been used to analyze patients in hospital discharge data - patient information was classified according to complexity of diseases and primary chronic conditions. That data was merged with hospital discharge data to identify what hospital services those patients used.

As a result of this data and methodology, Seattle Children's Hospital is launching a study that will examine how to improve the coordination of care for patients with lifelong chronic conditions, decrease their need for hospitalization and improve their quality of life. The study will follow approximately 600 of these medically complex patients for two years in a clinic that will work with patients' [primary care](#) providers to develop care plans and other interventions to improve their care and reduce the need for hospitalization.

"This will be the most comprehensive study of its kind," said Mark Del Beccaro, MD, pediatrician-in-chief at Seattle Children's Hospital. "If we succeed in showing we can improve care and lower costs for the patients and their families, this will also have tremendous implications nationally as these most complex and fragile of patients utilize a significant portion of health care expenditures in every community and state."

Provided by Seattle Children's

Citation: Study takes first steps to improve the quality of health care for chronically ill children (2010, November 16) retrieved 21 May 2024 from <https://medicalxpress.com/news/2010-11-quality-health-chronically-ill-children.html>

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