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The Need for An Automated Acuity Tool for Children With Special Health Care Needs

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INTRODUCTION

Children with special health care needs (CSHCN) are defined by the Maternal Health Bureau as those with a “chronic physical, developmental, behavioral, or emotional condition who require health and related services of a type of amount beyond that required by children generally.”

This group comprises between 13 and 18% of children in the United States. These children have been grouped together based on the premise that they all have certain health needs, but their medical complexities are compounded with additional non-health burdens. The number of CSHCN and children with chronic illness may even be increasing. Across the nation, the prevalence of asthma and obesity has tripled since the 1980s, and nearly 15% of children in the U.S. have a special health care need. Consequently, pediatric health teams will need to deal with more complex, time-demanding, and expensive cases – far different from the well-visits that define today’s pediatric clinic. Without an efficient and coordinated system of care, it will be difficult to care for these children.

Due to their chronic conditions, CSHCN require continuous contact with numerous health professionals. Their increased medical problems compound other non-medical strains on the child and family. Families of some CSHCN face daily challenges beyond that of other families in their communities, including additional direct and indirect financial pressures of caring for an ill child, missed school and work days, and difficulty with access to care. Additionally, given the low socioeconomic status of some families, lack of insurance, transportation and health literacy are often major factors that cripple families. By better understanding the additional burdens outside of the traditional medical encounter, it is possible to create a more efficient and fluid system to serve CSHCN.

A NEW DEFINITION OF QUALITY CARE

Chronic health concerns are not the only obstacles faced by CSHCN. The term “care” takes on a new meaning that extends beyond medications and physician visits, focusing on the needs of the patient and family (rather than organ systems or health systems) at the center of the medical home. Such family-centered care requires a network of doctors, nurses, coordinators, family and social support. Care coordination is considered an essential part of family-centered care for CSHCN with demonstrated cost savings and improved family satisfaction potentially affecting the children’s medical acuity and health outcomes. There are varying models for care coordination of CSHCN across the United States including care coordination originating in the primary care center, medical home, tertiary centers such as universities or children’s hospitals, and others institutions such as county health departments or statewide Title V programs. Turchi et al. showed that families that received adequate care coordination saw a decline in hospital/Emergency Department (ED) visits, fewer days of school missed, fewer problems with referrals to specialist, and fewer missed work days. Despite these benefits, however, families are often unaware or unsatisfied with systems of care; in the Turchi study, for example, 40% of families receiving care coordination found it to be inadequate or unsatisfactory.

Inadequate care coordination is partially explained by the strain of the growing caseloads with decreasing resources – particularly for publicly-funded programs and low-income communities. To address this strain while maintaining family-centered care, application of severity scores or risk stratification may be necessary to match the urgency and intensity of family needs with available resources (including care coordination). The most effective care-coordination pilots have been implemented with caseloads of fewer...
than 50 high-risk patients. While focusing resources on the highest risk CSHCN may be the most feasible and cost-effective solution for many health systems, it cannot entirely abandon the needs of lower-risk CSHCN. This caveat is a particularly true because of temporal concerns (a patient’s acuity status sometimes changes) and psychosocial and family-centered concerns (patient’s needs, even for “low risk” children, are real). Consequently, even in a caseload with 10-15% high risk patients, all 50 patients can eventually become high risk. Fortunately, there is a solution to the constantly fluctuating acuity status. One solution may be integrating within a large health system (e.g., Medicaid managed care or a new Accountable Care Organization) an acuity tool that would be administered regularly to provide the coordinators with the most updated risk classification for each patient. After thorough baseline acuity is established, a more streamlined version focused on more rapidly changing factors would be administered regularly. Consequently, the caseloads will be automatically reshuffled to produce a balanced load. Continuity of care will not be affected as patients will still be cared by the same health professionals.

AIMS OF AN ACUITY TOOL FOR CSHCN

An iterative effort involving health professionals from multiple disciplines including nursing, medicine, and health services research is necessary to design risk assessment tools to improve the delivery of care coordination for CSHCN. If successful, such a tool will benefit those who are reliant on public funding such as the Title V program, which serves children from low-income families who are insured by either Medicaid or the Children’s Health Insurance Program (CHIP). These families are also disproportionately from ethnic and language minority communities. The tool should be designed to more clearly align services and patient needs with provider skills and community resources. To do so, the tool should be able to categorize patients into one to three groups according to their acuity. Furthermore, any tool should describe not only biomedical or disease needs, but also modifiable psychosocial characteristics and needs. Evidence from decades of child health services research points to the powerful role of these modifiable psychosocial characteristics — particularly low socioeconomic status, English language proficiency, limited literacy skills, maternal mental health issues, and transportation barriers — as moderators or mediators of child health disparities. The automated acuity tool, itself, is not a novel idea; rather, the inclusion of psychosocial criteria in this tool finally accounts for social determinants that impact the health outcome of the child.

Any acuity tool should also combine information technology (IT or “automated” component) with human health professional input. The IT solution is necessary to reduce the inordinate amount of time health professionals (including care coordinators) currently spend reassessing the risk level of each patient, while they could be using this time to facilitate better health outcomes. Finally, any acuity assessment tool should be rapidly deployable and prospectively validated against meaningful health outcomes (e.g., health-service utilization cost of care, quality of care, and quality of life).

REGIONALIZATION: SOUTH FLORIDA AS A CASE STUDY

Health systems, and reform of health systems, have historically and will continue to be state-implemented and regulated affairs. The consequences for CSHCN of health reform, then, will be borne out state by state.

In South Florida, for example, the population of CSHCN primarily consists of low-income, minority families with language barriers. Using the data from the National Survey of CSHCN from 2001 to 2006, Blumberg found that Hispanic children from a primarily Spanish-speaking household were only one-third as likely as other kids to be identified as CSHCN. This large difference may be a valid finding, or it is also possible that there is a serious problem with underidentification given the access and language barriers. Even after they are diagnosed, Hispanic populations with limited English proficiency and other vulnerable ethnic minorities still have diminished access to resources. This is emphasized by Blumberg’s research that this group of Hispanic children from Spanish-speaking homes was unlikely to have visited the doctor in the past year due to a lack
of resources. Care coordination will overcome this barrier by facilitating access to resources. Additionally, there is a lower level of medication compliance suggesting a generational and cultural perception of the efficacy of medical treatment. This dynamic emphasizes that CSHCN of Hispanic origins from Spanish-speaking homes often have other barriers beyond their medical condition to achieving healthy outcomes. These trends regarding the Hispanic population were observed in the 2001 National Survey of CSHCN. The results showed that while approximately 70% of the CSHCN were mostly white, a significant minority, 21.1%, were Hispanic. This number will continue to increase as the population of Hispanic individuals continues to grow in this country. It is estimated that approximately 1 in 4 children will be of Hispanic origin by 2020. Literacy will be one of the major factors as 50% of Hispanic children live in homes where the primary language is Spanish. Not only will language affect communication, but it will also impact access and the cultural stereotypes of health care. Consequently, this issue is not so unique to South Florida and should be considered nationally.

The work to reform the current system of care is more important than ever as Florida, like most other states, is faced with extremely tough economic times. Recent cuts to federal and state programs nationwide have resulted in dramatically increased strain on these systems of care, including increased numbers of enrollees in public health insurance programs, decreased numbers of care coordinators, and subsequent increases in caseloads (often greater than 300 patients per care coordinator). An automated acuity tool that delivers effective care coordination is cost-effective in the long term by reducing out-of-pocket costs and unnecessary ED and doctors visits while still providing a high level of care and commitment. Private health insurance companies such as Blue Cross Blue Shield of Massachusetts are already using similar tools in order to obtain quantifiable acuity data which they can use to determine caseloads and staff numbers. Therefore, the successful implementation of an acuity tool may have large implications for public health insurance programs in this country.

CONCLUSION
An acuity tool will allow clinicians and policymakers to deal with the growing problem of special needs and chronic conditions within the established structure of pediatric care. Physicians and nurses can receive the most updated risk assessment for their patients and focus their time accordingly. Consequently, it will utilize a more holistic approach to caring for the entire patient population rather than just one child at a time. The pediatric community has led the way before in advancing health care delivery. The medical home model was developed with children in mind and, only then, implemented for the care of adults. Researchers have already made the medical advances to combat the severe illnesses; the pediatric community must now make the parallel developments in the health care systems. With the successful implementation of the acuity tool, it is possible to once again lead the way in improving the systems of care that serve CSHCN.

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REFERENCES


