Ways to Identify Children with Medical Complexity and the Importance of Why

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Children with medical complexity, although a small fraction of the pediatric population, are important due to their high levels of healthcare spending, unmet healthcare needs, substandard quality of care, and poor health outcomes.[1] Consistent with the Triple Aim,[2] these children are the focus of clinical, research, and policy initiatives seeking to: (1) improve their healthcare experience and quality of care; (2) improve outcomes (for themselves and their families); and (3) reduce the future healthcare costs that they might accrue.[3-8] Clinics, hospitals, states, and countries throughout the world are reforming the health system to optimize its performance for children with medical complexity.[9,10]

Although the act of recognizing that a particular child is medically complex may seem straightforward at the individual level, identifying children with medical complexity at a population level is not straightforward. At the individual level, recognizing medical complexity is a subjective distinction,[11] drawing on a person's experiences and perceptions of viewing a child as being medically complex.[12] When scaled up to population-level, 3 challenges emerge. First, the construct of medical complexity is regarded differently among parents, clinicians, researchers, and others. Second, individual-level details about the child that are evident or discoverable in a one-on-one, in-person encounter (eg, an outpatient clinic visit) are often not readily available in population-level data sources. Third, in contrast to their adult counterparts, children with medical complexity have a heterogeneous array of rare health problems without a select few that dominate in prevalence and impact.

With these caveats in mind, we review existing techniques and tools that can be used to identify children with medical complexity from a variety of health data sources, including administrative billing data and parent- or provider-reported survey. We organize our review with Cohen et al children with medical complexity definitional framework of interacting characteristics, including complex chronic health problems, substantial healthcare needs, severe functional limitations, and high health resource utilization.[1] Moving stepwise through this framework, we focus on the advantages and disadvantages of various approaches to identify children with medical complexity.

Identifying the Complex, Chronic Health Problems Endured by Children with Medical Complexity

Most health problems endured by children with medical complexity are burdensome, severe, life-long, and incurable. Some health problems are inherently complex because their rarity and complicated pathophysiology preclude most clinicians from becoming proficient in understanding and managing them (eg, ornithine transcarbamylase deficiency). Other health problems that may not be considered complex in isolation become complex in combination (eg, asthma, depression, and type I diabetes mellitus) because of their clinical interactions, their additive effects on health status and quality of life, and the care coordination required to manage the problems among multiple providers.

Comprehensive identification of children with medical complexity is dependent upon methods that are capable of distinguishing these diagnosis situations and others that lead to complexity. We compare and contrast 4 examples of diagnosis classification systems that have been used to identify the health problems endured by children with medical complexity from *International Classification of Diseases* (ICD) diagnosis and procedure codes (Table I). Although other systems may exist, to our knowledge the 4 examples below are the most pertinent to the identification of children with medical complexity.

Complex Chronic Conditions
Complex chronic conditions (CCCs) are an open-source set of childhood complex, chronic health conditions that are strongly associated with mortality, morbidity, functional limitations, high health resource utilization, and use of a

CCC	Complex chronic condition
CCI	Chronic condition indicator
CRG	Clinical risk group
ICD	*International Classification of Diseases*
ICD9	ICD Ninth Revision
ICD10	ICD Tenth Revision
NS-CSHCN	National Survey of Children with Special Healthcare Needs
PEDI-CAT	Pediatric Evaluation of Disability Inventory Computer Adaptive Test
PMCA	Patient medical complexity algorithm

Table I. Four examples of tools to identify the health problems endured by children with medical complexity

Attributes	ICD code diagnosis classification systems			
	CCCs	CRGs	Chronic condition indicator	Patient medical complexity algorithm
Developer	Feudtner et al[15]	3M Health Systems	AHRQ	Seattle Children's Hospital Center of Excellence on Quality of Care Measures for Children with Complex Needs
Specific to pediatric patients	Yes	Yes	No	Yes
Number and type of clinical categories	12 major categories 75 subcategories	9 major categories with numerous subcategories	18 major categories 567 subcategories	3 major categories* 7 subcategories
Clinical categories specific or relevant to children with medical complexity	All	Major categories 5b-9 or 6-9	No	1 major category
Contains a definition of a complex health problem:	Yes. A CCC is one that "can be reasonably expected to last at least 12 mo (unless death intervenes) and to involve either different organ systems or 1 organ system severe enough to require specialty pediatric care and probably some period of hospitalization in a tertiary care center."	No	No	Yes. A complex chronic disease is: "a significant chronic condition in 2 or more body systems" or "a progressive condition that is associated with deteriorating health with a decreased life expectancy in adulthood" or "associated with continuous dependence on technology lasting for at least 6 mo" or "a metastatic or progressive malignancies that affect life function, (excluding) those in remission for >5 y"
Can identify "noncomplex" chronic conditions	No	Yes	Yes	Yes
Populations of children not included	Children with behavioral/ mental health, non-CCCs, or no chronic condition	All children can be included†	All children are included	All children can be included†
Capable of identifying children with multiple chronic conditions	Yes, for children with multiple, CCCs only	Yes	Yes	Yes
Capable of distinguishing discrete diagnoses	Yes, with the subcategories	Yes, with the subcategories (ie, episode diagnosis categories)	Yes, with the subcategories (ie, lowest-level CCS categories)	Yes
Open-Source	Yes	No. Licensing costs are determined by the number of patients on which the CRGs will be used.	Yes	Yes
Compatible with ICD10	Yes	Yes	Yes	No
Amount of data recommended for use	ICD diagnosis codes from any single medical encounter	ICD codes aggregated across a 3-y period of time from both inpatient and outpatient data sources.	ICD diagnosis codes from any single medical encounter	ICD codes aggregated across a 2-y period of time from both inpatient and outpatient data sources.
Examples of use in children with medical complexity	• Predicting death[15] • Predicting hospital readmission[46,47] • Describing the clinical characteristics of palliative care patients[48] • Describing children enrolled in a complex care program[4] • Describing healthcare use and spending for populations of Children with medical complexity[13,49]	• Assessing population growth of patients in children's hospitals[20] • Describing healthcare use and spending for populations of children in health plans[17,50,51] • Stratifying children by medical complexity[21]	• Assessing risk factors for hospital readmission in children[26] • Counting the number of chronic conditions in children with medical complexity[45]	• Identifying children with medical complexity using Medicaid claims data[27]

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