

## Shared Decision Making among Children with Medical Complexity: Results from a Population-Based Survey

Jody L. Lin, MD<sup>1</sup>, Eyal Cohen, MD, MSc<sup>2</sup>, and Lee M. Sanders, MD, MPH<sup>3</sup>

**Objective** To compare the rates of shared decision making (SDM) reported by parents of children with medical complexity (CMC) with the rates of SDM reported by parents of noncomplex children with special health care needs (CSHCN).

**Study design** We examined the 2009-2010 National Survey of Children with Special Health Care Needs, a representative survey of 40 242 parents of CSHCN. CMC was defined as needing or using more medical care than usual, seeing 2 or more subspecialists, and positive response on at least 3 other items on the CSHCN screener. We identified 3 subgroups each of CMC and noncomplex CSHCN by sentinel diagnoses: asthma, seizures, and other diagnoses. SDM was defined as a binary composite variable, derived from 4 discrete items. We constructed 4 stepwise multivariable models to assess the relative odds of SDM, adjusted for sociodemographic characteristics (age, income, language, race, ethnicity, and marital status), behavioral comorbidity, family-centered care, and patient-centered medical home.

**Results** The study population included 39 876 respondents. Compared with noncomplex CSHCN, CMC had a lower likelihood of SDM (aOR, 0.76; 95% CI, 0.64-0.91), which persisted in diagnostic subgroups: CMC with asthma (aOR, 0.67; 95% CI, 0.49-0.92) and CMC with other diagnoses (aOR, 0.74; 95% CI, 0.58-0.94), but not CMC with seizures (aOR, 0.95; 95% CI, 0.59-1.51).

**Conclusions** SDM is less common for CSHCN with complex needs than those without complex needs. Health system interventions targeting future-oriented care planning may improve SDM for CMC. (*J Pediatr* 2017;■■■:■■■-■■■).

Shared decision making (SDM) is a central component of quality care for patients with chronic illnesses.<sup>1</sup> SDM uses bidirectional exchange of information between providers, patients, and caregivers to reach treatment plan agreement.<sup>2-4</sup> Essential elements of SDM include defining the problem, presenting options, elucidating patient and provider preferences, and assessing patient self-efficacy.<sup>5</sup> SDM facilitates productive interactions between the medical team, patient, and caregivers, particularly in situations of clinical uncertainty without a best treatment option.<sup>6,7</sup>

SDM is thought to be important for preventing ambulatory care sensitive hospitalizations.<sup>8</sup> Prior studies suggest that SDM improves care quality for adults with heart failure and type 2 diabetes, and may reduce health inequalities for populations with lower literacy and lower self-efficacy.<sup>9</sup> In children, SDM is associated with decreased disease severity in asthma, Attention Deficit Hyperactivity Disorder, and type 1 diabetes.<sup>10-13</sup> Among all children with special health care needs (CSHCN), parent report of low SDM is associated with increased functional disability, public insurance, and higher out-of-pocket expenses.<sup>14,15</sup>

Children with medical complexity (CMC) are a subset of CSHCN with high service needs, high resource use, and, often, severe functional disability.<sup>16</sup> CMC comprise less than 5% of the US child population and receive poorer quality care, but consume more than 30% of child healthcare expenses.<sup>16-19</sup> According to the American Academy of Pediatrics, SDM is crucial for improving the health and satisfaction of children with disabilities and is the basis for patient-centered care.<sup>4</sup> Care coordination across clinical settings and subspecialties may improve care quality for CMC, but providers' poor communication skills sometimes hinder effective care coordination.<sup>18,20,21</sup> Tools that promote SDM may improve parent-provider communication through the integration of parent's understanding, values, and self-efficacy.<sup>5,22</sup> SDM is particularly crucial for CMC, because it enables the alignment of care decisions longitudinally in a patient population whose multiple providers, complex illnesses, and frequent hospitalizations put them at high risk for

From the <sup>1</sup>Division of Pediatric Hospital Medicine, Stanford University, Department of Pediatrics, Palo Alto, CA; <sup>2</sup>Division of Pediatric Medicine, Hospital for Sick Children, Department of Pediatrics and Institute of Health Policy, Management, and Evaluation, University of Toronto, Toronto, Ontario, Canada; and <sup>3</sup>Division of General Pediatrics, Stanford University, Department of Pediatrics, Stanford, CA

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CMC	Child(ren) with medical complexity
CSHCN	Children with special health care needs
FCC	Family-centered care
NS-CSHCN	National Survey of Children with Special Healthcare Needs
PCMH	Patient-centered medical home
SDM	Shared decision making

fragmented, episodic care that can precipitate health crises. Little is known, however, about the prevalence and impact of SDM for CMC.<sup>10,14,20</sup>

The purpose of this study is to compare parent-reported rates of SDM for CMC and noncomplex CSHCN. We hypothesized that CMC would report lower SDM than noncomplex CSHCN and that this difference would persist when comparing children with similar sentinel diagnoses.

## Methods

We conducted a cross-sectional analysis of the 2009-2010 National Survey of Children with Special Healthcare Needs (NS-CSHCN), a population-based evaluation of care quality for CSHCN representative of CSHCN nationally and by state.<sup>23-25</sup> This version of the survey included a revised set of SDM questions felt to capture key elements of SDM with more reliability and validity as reflected by thought leaders and parents of CSHCN through multiple cognitive interviews.<sup>14</sup> Conducted by the National Center for Health Statistics through a random-digit dialing system of landlines and cell phone numbers, parents with a positive response to at least 1 domain of the CSHCN screener screen into the survey.<sup>26</sup> If multiple children are eligible, 1 child is selected randomly as the focus of the survey.

We examined all 40 242 survey responses from the 2009-2010 NS-CSHCN dataset. After excluding responses missing the SDM composite score (described elsewhere in this article), 39 876 (99.1%) of all surveys were available for analysis.

The primary outcome variable was SDM as assessed by 4 survey items.<sup>27</sup> On a 4-point Likert scale (never, sometimes, usually, or always), each parent reported their frequency for receiving each of the following from their child's medical providers: discussed a range of treatment options, encouraged to ask questions or raise concerns, made it easy to ask questions or raise concerns, and considered and respected family's treatment choices. Positive SDM was defined as parent report of "usually" or "always" on all 4 items.<sup>27</sup>

The main predictor variable was CMC, defined in prior studies of the NS-CSHCN as a child meeting all of the following 3 criteria: (1) need for more medical care than usual, (2) positive responses to at least 3 of 4 remaining screener items (increased functional limitations, need for prescription medications, special therapies, or developmental and behavioral treatment), and (3) visits to 2 or more subspecialists in the last 12 months.<sup>16,19</sup> All children not classified as CMC were classified as noncomplex CSHCN.

Three subgroups of both CMC and noncomplex CSHCN were defined based on the presence of the following sentinel diagnoses: (1) asthma, (2) seizure disorder, or (3) other diagnoses (ie, neither asthma nor seizure disorder), with children with both asthma and seizures represented in both subgroups. These subgroups were chosen for comparison owing to the known positive effects of SDM on health outcomes in noncomplex CSHCN with asthma and the relatively high prevalence of childhood seizure disorder and asthma.<sup>12,28,29</sup> Children with seizure disorder account for more than 50% of

hospitalizations in children with neurologic impairment, a subgroup of CSHCN known for high health resource use.<sup>30</sup> High hospital resource use could signal poor care quality, including low SDM. Other chronic conditions with known positive outcomes associated with SDM, such as type 1 diabetes, were not prevalent enough in the cohort to warrant separate comparisons and were combined into the "other diagnoses" category.<sup>13</sup>

For unadjusted and adjusted analyses, we examined any measurable child characteristics that have been shown in prior studies to be associated with the likelihood of receiving SDM, identification as CMC, or diagnoses of asthma or seizures. Child- and family-level demographic and clinical characteristics assessed included child age, race/ethnicity, maternal education, household language, household income, insurance type, functional limitation, and behavioral comorbidity. Functional limitation was divided into 3 strata (never affected, moderately affected, or a great deal affected) as described in prior studies.<sup>14</sup> Children with epilepsy have increased behavioral comorbidities compared with children without epilepsy.<sup>31-33</sup> Using previously described patterns of behavioral comorbidities in children with epilepsy, behavioral comorbidity was defined as having 1 or more of: Attention Deficit Hyperactivity Disorder, depression, anxiety, or behavioral disorders such as conduct disorder or oppositional defiant disorder.<sup>31,32</sup> Health system-level characteristics assessed for each child included family-centered care (FCC) and patient-centered medical home (PCMH), composite measures with detailed methodology presented elsewhere.<sup>34,35</sup>

## Statistical Analyses

Descriptive statistics for sample characteristics were weighted to reflect US population-level estimates using sampling weights provided by the NS-CSHCN.<sup>27</sup> Weighted categorical percentages were compared across all children (CMC vs noncomplex CSHCN) and across subgroups stratified by sentinel diagnoses (asthma, seizure disorder, other). Bivariate comparisons were assessed with the Student *t* test for continuous data and with Rao-Scott  $\chi^2$  test for categorical data.

Multiple logistic regression models were generated to assess the relationship between SDM and complexity (CMC vs noncomplex CSHCN) for each sentinel diagnosis. Covariates were selected based on a relative difference of at least 10% in the OR for SDM and complexity (CMC vs noncomplex CSHCN) before versus after adjusting for the covariate.<sup>36</sup> Modeling applied covariates in a stepwise fashion. This included an unadjusted model (model 1) and models adjusted for sociodemographic characteristics (model 2: child age, ethnicity, insurance and parent income, language, education, marital status), behavioral comorbidities (model 3), health provider factors (model 4: FCC), and health system factors (model 5: PCMH). FCC was evaluated before PCMH because FCC is a nested subdomain of PCMH, but is not an anchoring subcomponent of the composite PCMH measure.<sup>27,37</sup> Owing to previously well-described rates of SDM in noncomplex CSHCN with asthma, and associations between SDM and better asthma outcomes in noncomplex CSHCN with asthma after using an

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