National and State Findings on Shared Decision-Making for Children with Special Health Care Needs: Prevalence, Variations and Psychometric Properties

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Background

Shared decision making (SDM) is a critical component of patient engagement and family-centered care.[1] It is a national quality measurement priority recognized by the American Academy of Pediatrics and the US Department of Health & Human Services.[1,2] It is also specified as a national system performance measure for children with special health care needs (CSHCN) by the Federal Maternal & Child Health Bureau (MCHB).[3] The measurement of shared decision making was redesigned for the 2009/10 National Survey of Children with Special Health Care Needs (NS-CSHCN).

Objectives

We had three objectives: (1) to evaluate the psychometric properties of the shared decision making (SDM) measure in the 2009/10 NS-CSHCN; (2) to estimate national prevalence, geographic disparities and sociodemographic variations in SDM among CSHCN; and (3) to assess the associations between SDM and the complexity of health needs, health and well-being and other measures of health care quality for CSHCN.

Methods

Data for this study come from the 2009/10 National Survey of Children with Special Health Care Needs (NS-CSHCN) and were collected between July 2009 and March 2011.[4] The survey is directed and funded by the Maternal and Child Health Bureau of the Health Resources and Services Administration and administered by the National Center for Health Statistics using the State and Local Area Integrated Telephone Survey mechanism. The sample represented at least 750 children with special health care needs (CSHCN) from each state and DC (751-878 per state).[4] All estimates are adjusted for nonresponse bias and weighted to represent the noninstitutionalized population of CSHCN age 0 to 17 years nationwide and in each state. Children with special health care needs were identified using the standardized CSHCN Screener.[5] The survey items used for the shared decision making measure are shown in Table 1.

Table 1: Survey Items Included in the Shared Decision Making Measure

Introduction: We want to know about how [child]'s doctors or other health care providers work with you to make decisions about [his/her] health care services and treatment.

During the past 12 months/Since [his/her] birth…

1. How often did [child]'s doctors or other health care providers discuss with you the range of options[+] to consider for [his/her] health care treatment?
2. How often did they encourage you to ask questions or raise concerns?
3. How often did they make it easy for you to ask questions or raise concerns?
4. How often did they consider and respect what health care and treatment choices you thought would work best for [him/her]?

Scoring: The shared decision making measure is met if the child's parent responded "usually" or "always" to all 4 items above.

[+] Parents are read the following if necessary: 'the options may include things like whether or not to start, stop or change a medication, treatment or therapy; whether to have certain tests or procedures, see a specialist, consent for surgery, and so on.'

Cognitive testing findings were summarized and item response and convergent and divergent validity assessments were performed. National and state level SDM prevalence was calculated across a range of child subgroups and states. Multivariate logistic regression models examined associations between SDM and complexity of special health care needs and health conditions, socioeconomic status, health insurance, and other measures of health care quality, such as medical home and patient-provider communication. For bivariate analyses, standard t-tests or chi-square tests of statistical differences were used. Multivariate analyses (adjusted odds ratios, AORs) control for child's age, sex, race/ethnicity, parental education and household income.

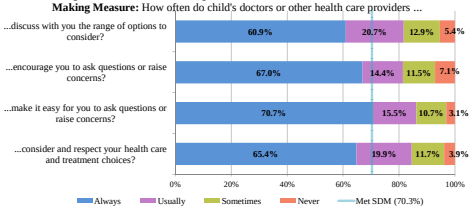
Results

Cognitive Interview Findings and Psychometric Properties

The four shared decision making items were iteratively specified after 12 rounds of cognitive interviews, where numerous candidate items were tested. Items were then pretested with 132 households with children. Cognitive testing with parents of CSHCN showed final versions of the introduction and four questions had face validity, were understood as intended and reliable. Family focus groups before and during development confirmed the four items represented most essential components of shared decision making. Additional items were also relevant, but survey space limits prevented their inclusion. Cronbach's Alpha for the SDM items was 0.868, indicating high internal consistency. Cronbach's Alpha was lower if any item was deleted, indicating that none should be removed from the measure. Item correlations demonstrated linked but differentiated information is provided by each item, with correlations ranging from 0.592 to 0.686. Corrected item-total correlations ranged from 0.679 to 0.765, indicating each item is correlated with the measure as a whole (not including that item).

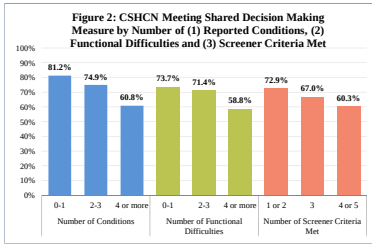
Shared decision making is positively correlated with both having a medical home and receipt of family centered care (Pearson Correlation p-value <0.001). CSHCN who meet medical home criteria are 6.48 times more likely to meet SDM criteria than CSHCN who do not meet medical home criteria (AOR 95% CI: 5.82-7.22). CSHCN who receive family-centered care (FCC, a component of medical home) are 9.96 times more likely to meet SDM criteria than CSHCN who do not receive FCC (AOR 95% CI: 9.05-10.95).

Figure 1: Distribution of Response for Each item in the Shared Decision Making Measure: How often do child's doctors or other health care providers ...



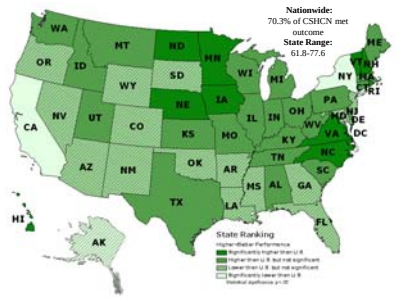
Nationally, 70.3% of CSHCN met the SDM measure (Figure 1). This means the respondent (typically the child's parent or guardian) answered "usually" or "always" to all four questions comprising the measure (blue or pink in the graph above). Of the four items, parents were least likely to respond that their child's doctors or health care providers usually or always encourage them to ask questions or raise concerns; however, 81.4% of CSHCN still met this component of the measure. For each question, only a small proportion of CSHCN had a parent who answered "never" (coral bars in Figure 1).

Figure 2: CSHCN Meeting Shared Decision Making Measure by Number of (1) Reported Conditions, (2) Functional Difficulties and (3) Screener Criteria Met



As number of conditions, number of difficulties, and number of CSHCN Screener criteria met increases, the likelihood that CSHCN meet the shared decision making measure decreases.

Figure 3: Geographic Variations in Shared Decision Making



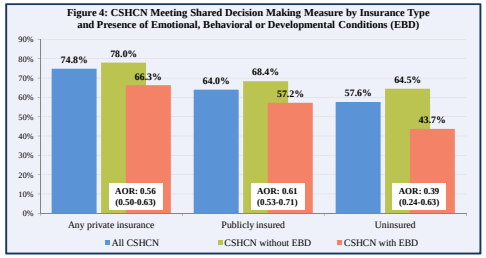
Geographic Variations (Figure 3)

- For most states, the percent of CSHCN meeting SDM is not statistically different from the national average of 70.3%.
- California and New York are the only two states that perform statistically significantly worse than the national average
- Ten states perform significantly better than the national average

Demographic Variations

- Race/ethnicity: 74.2% for White/non-Hispanic CSHCN versus 64.6% for non-White/Hispanic or non-Hispanic CSHCN
- Income: 61.8% for CSHCN living under the federal poverty level (FPL) to 77.2% for CSHCN living at 400% FPL or above
- Household education level: 58.8% for less than high school, 66.2% for high school graduate and 73.3% for anything beyond high school
- No substantial variations by age or gender

Figure 4: CSHCN Meeting Shared Decision Making Measure by Insurance Type and Presence of Emotional, Behavioral or Developmental Conditions (EBD)



CSHCN with ongoing emotional, behavioral or developmental conditions (EBD; 31.8% of CSHCN and 4.8% of all children) are less likely to meet the SDM measure than other CSHCN:

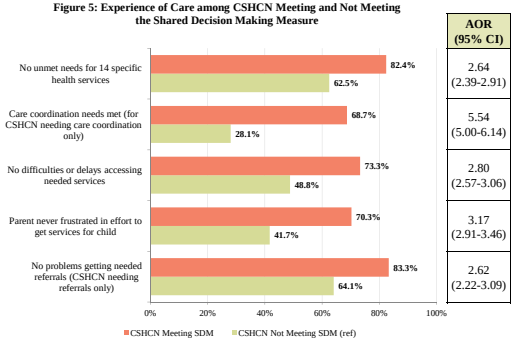
- For all CSHCN, the AOR is 0.57 (95% CI: 0.52-0.62)
- Similar odds ratios are seen when results are stratified by insurance type - the difference is especially pronounced for uninsured CSHCN

SDM varies by insurance type and adequacy:

- Publicly insured and uninsured CSHCN are less likely than privately insured CSHCN to meet SDM, with AORs of 0.79 (95% CI: 0.70-0.90) and 0.58 (95% CI: 0.45-0.74), respectively
- CSHCN with adequate insurance have odds of meeting the SDM measure that are over 2.6 times the odds for CSHCN with inadequate insurance (AOR=2.61, 95% CI: 2.39-2.86)

Results

Figure 5: Experience of Care among CSHCN Meeting and Not Meeting the Shared Decision Making Measure



	AOR (95% CI)
No unmet needs for 14 specific health services	2.64 (2.39-2.91)
Care coordination needs met (for CSHCN needing care coordination only)	5.54 (5.00-6.14)
No difficulties or delays accessing needed services	2.80 (2.57-3.06)
Parent never frustrated in effort to get services for child	3.17 (2.91-3.46)
No problems getting needed referrals (CSHCN needing referrals only)	2.62 (2.22-3.09)

Shared decision making is positively associated with other measures of a high quality care experience (Figure 5). Compared to CSHCN who do not meet the SDM measure, CSHCN who meet it are more likely to have:

(1) no unmet needs for any of 14 specific health services
(2) their care coordination needs met
(3) no difficulties or delays accessing needed services
(4) a parent who is never frustrated in their efforts to get services for the child
(5) no problems getting needed referrals

These differences are statistically significant after controlling for age, sex, race/ethnicity, household income and parental education. The large association between SDM and receipt of effective care coordination (among CSHCN needing care coordination) is especially noteworthy.

Discussion

Shared decision making is associated with positive experiences seeking care and fewer unmet needs but varies widely across states. SDM is a nationally recognized priority, but the prevalence remains low among some subgroups of CSHCN. Wide state and insurance type variations highlight opportunities for learning and quality improvement. Variations between this measure of SDM and other measures of patient-provider communication highlight the complexities of measuring shared decision making. Psychometric findings support the validity and reliability of the SDM measure, but focus groups with families indicate additional concepts are involved in effective provider-family partnerships beyond those included in the SDM measure. Shared decision making is an integral component of quality health care for CSHCN that improves patients' experience with care and increases the probability that needs are met. The four items used to assess SDM in the 2009/10 NS-CSHCN may not capture all of the intricacies of SDM but can be used as a concise and standard tool for monitoring progress and assessing disparities on this key concept within the broader topic of patient engagement, activation and partnership.

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