Published in final edited form as:

Matern Child Health J. 2015 June ; 19(6): 1384–1392. doi:10.1007/s10995-014-1644-3.

Strategies to Identify and Stratify Children with Special Health Care Needs in Outpatient General Pediatrics Settings

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Abstract

Developing improved systems of care for children with special health care needs (CSHCN) requires accurate identification and stratification of this population. This study was designed to assess the ability of a brief screener to identify and stratify CSHCN in a primary care clinic to focus future quality improvement initiatives and allocate resources. All families presenting for health maintenance visits or acute care appointments at an academic primary care clinic between September 5, 2012 and September 28, 2012 were asked to complete the CSHCN Screener[®]. This panel of patients was compared to registries previously created by: (1) retrospective chart reviews using published lists of International Statistical Classification of Diseases and Related Health Problems (ICD9) codes for CSHCN and (2) direct physician referral to a clinic case manager providing care coordination services to CSHCN. Screeners identified 246 CSHCN (16.8 % of unique completed screeners). Scores ranged from 0 to 5; higher scores indicate higher levels of complexity. Patients with positive screens had a mean score of 2.4. Patients previously identified by retrospective ICD9 search who completed a screener had a mean score of 1.6 with nearly one-half having negative screens. Patients previously identified by physician referral who completed a screener had a mean score of 2.7 with nearly one-half having scores of 4 or 5. The CSHCN

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Conflict of interest The authors have no financial relationships relevant to this article to disclose. The authors have no conflicts of interest to disclose.

Screeener[®] can be utilized in an academic primary care clinic to prospectively identify CSHCN and potentially offers a more clinically meaningful method of identification given its inherent ability to stratify this population based on complexity of medical needs.

Keywords

Children with special health care needs; Children with medical complexity; Medical home; Primary care; Quality improvement

Introduction

The Maternal and Child Health Bureau defines children with special health care needs (CSHCN) as “those who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and health related services of a type or amount beyond that required by children generally” [1]. Although CSHCN only represent an estimated 13–20 % of all children, they account for as high as 70 % of pediatric health care expenditures [2–5]. With the growing population of CSHCN [6], continued efforts to develop and improve health care systems for this vulnerable population need to be prioritized.

Accurate identification of CSHCN is the first step in developing improved health care systems for this population. The Maternal and Child Health Bureau definition has become widely adopted, yet no gold standard method for identification has been specified for clinical settings. Furthermore, the definition is broad and does not provide insight regarding stratification of CSHCN based on level of medical complexity. Stratification of this population is essential in order to appropriately allocate limited resources [7, 8], particularly since 1 % of patients with the highest level of medical complexity at any one time account for over one-third of pediatric health care cost based on insurance charges [9], which does not include the additional costs to families and caregivers that exist in regards to actual expenditures, lost wages, and psychosocial stress. Prior research demonstrates that effective out-patient primary care can improve health outcomes and decrease costs for CSHCN [10–13], but in order to accomplish such goals one must first be able to identify this population of children within a clinic setting.

One method for identifying and stratifying CSHCN involves using screening questionnaires. While there are a variety of screening tools available to identify CSHCN, the CSHCN Screeener[®] (Fig. 1) has several advantages [14]. The CSHCN Screeener[®] is a five item questionnaire introduced in 2002 that operationalizes the widely accepted definition from the Maternal and Child Health Bureau. It uses a health consequence-based approach, thereby excluding the “at risk” component of this definition and avoiding limitations associated with reliance on specific diagnoses or International Statistical Classification of Diseases and Related Health Problems (ICD9) codes. It was designed by a collaborative workgroup and has been shown to have both face validity and convergent validity when compared to more extensive screening questionnaires, as well as high internal reliability [15–17]. It also offers a means for stratification of the population of CSHCN according to their level of complexity, because studies show that increased number of qualifying health consequences (i.e.

increased total screener score) correlates with overall poorer reported health status, unmet needs, and increased health care utilization and expenditures [18].

While the CSHCN Screener[®] has been used in population-based surveys and to identify a denominator for quality measurement purposes [19], less is known about its utility in a clinical setting. Furthermore, use of a brief screener to identify and stratify CSHCN in an outpatient setting to develop a registry for quality improvement initiatives and resource allocation has not been comprehensively compared to other utilized methods in such a setting. The objective of this study was to determine if the CSHCN Screener[®] could serve as a strategy to prospectively identify and stratify CSHCN in a clinic setting, and to compare its use to two other methods previously used for CSCHN identification in our clinic: retrospective chart reviews using published lists of ICD9 codes for CSHCN and direct physician referral to a clinic case manager providing care coordination services to CSHCN.

Methods

Permission to use the published English and Spanish versions of the CSHCN Screener[®] and to have the screener translated into Arabic for this project was obtained from the principal investigator for the development and validation reports of the screener, Dr. Christina Bethell. The Spanish version was reviewed by the clinic interpreter to ensure clarity for our patient population, and the Arabic version was created by the institution's formal translation services. These were the three most common languages spoken in the tested setting, an academic pediatric primary care clinic. If the family spoke a language other than one of these languages, the screener was completed with the assistance of an on-site interpreter if present.

The Vanderbilt Pediatric Primary Care Clinic is a resident-run clinic within an academic tertiary hospital that provides acute and well-child care to a primarily underserved population. The clinic serves approximately 16,000 patients with over 40,000 visits per year. The CSHCN Screener[®] was distributed to all children arriving at the clinic for either a health maintenance visit (well child check or chronic condition management appointment) or an acute care need between the dates of September 5, 2012 and September 28, 2012. The one-page screener was distributed to the parent or other caregiver during the check-in process by the front desk staff with instructions to self-administer the screener while waiting for his/her child's appointment. The screener was collected by clinic staff and scored by the principal investigator and one research assistant using the standard quantitative scoring method (view details regarding standard scoring for the screener at <http://cahmi.org/ViewDocument.aspx?DocumentID=115>). If a patient had multiple appointments during the collection period, only the first completed screener was scored. Incomplete or illegible screeners were not scored. The screener scores ranged from 0 to 5. Scores from 1 to 5 indicate a positive screen (i.e. the child has an identified special health care need). Higher scores indicate that the patient met a greater number of screening criteria (i.e. the child has a higher complexity of health care needs) [18]. For each patient with a scored screener, medical record numbers and demographic data were entered into REDCap, a secure web-based application designed to support data capture for research studies [20]. Institutional

Review Board approval was waived for this study since it met criteria for quality improvement work.

Analysis of the CSHCN Screener[®] was completed in two phases. First, the number and distribution of positive screeners for our clinic population, as well as their demographics, were compared to national statistics for CSHCN provided by the National Survey of CSHCN. Next, use of the CSHCN Screener[®] was compared to two previously used strategies for identification of CSHCN in our clinic. The first of these methods was retrospective chart reviews using selected sets of ICD9 codes from the literature that had been used to identify CSHCN for research purposes [21–23]. A combination of published ICD9 lists was used in order to compile a comprehensive registry of patients. The search was executed by query of the electronic medical record, which was not able to distinguish between outpatient and inpatient encounters. This process was completed in January 2010 and identified 1,830 CSHCN in our clinic who had been seen for annual well-child checks within the last 3 years. The second of these methods involved direct physician referral to the clinic case manager for care coordination service between January 2010 and September 2012. This process yielded a separate registry of 134 CSHCN in our clinic. Aggregate mean screener scores for patients previously identified by ICD9 search ($n = 107$) and case manager referral ($n = 22$) methods were calculated, and the distribution of scores for these cohorts were examined in an effort to compare varying methods for identification of CSHCN. Two-sample t tests for continuous variable comparisons and Pearson χ^2 tests for categorical variable comparisons were completed.

Results

There were 2,866 completed appointments during the study period and 1,806 screeners were collected (63 % of completed appointments). Of the collected screeners, 81 % were scored ($n = 1,467$); 251 screeners were excluded due to incomplete or illegible answers, and 88 screeners (77 negative and 11 positive) were excluded for patients that had multiple appointments during the study period (Fig. 2).

Demographic data for the scored screeners appears in Table 1. Relatively equal numbers of scored screeners were completed by males and females [51.5 % (755) and 48.5 % (712), respectively]. The mean age for children who had a scored screener was 4.1 years. Approximately three-quarters of the scored screeners were completed in English, nearly one-quarter in Spanish, and less than 5 % in Arabic. A higher proportion of positive screeners were completed by families of male patients (65.9 vs. 34.1 %, $p < 0.001$). There was a statistically significant difference in mean age of patients with positive and negative screeners, 6.6 versus 3.6 years, respectively ($p < 0.001$). Within the Caucasian population 21.4 % (73/341) of the scored screeners were positive, within the African American/Black population 19.7 % (116/590) were positive, and within the Hispanic/Latino population 10 % (41/412) were positive. There was a statistically significant difference in distribution of the four mutually exclusive race/ethnicity groups between positive and negative screeners ($p < 0.001$).

Screeners identified 246 CSHCN (16.8 % of the scored screeners). The distribution of positive screener scores was as follows: 105 patients had a score of 1 (42.7 %); 33 patients had a score of 2 (13.4 %); 40 patients had a score of 3 (16.3 %), 33 patients had a score of 4 (13.4 %), and 35 patients had a score of 5 (14.2 %) (Fig. 1).

The mean screener score for all patients with positive screens was 2.4. Patients previously identified as CSHCN by retrospective ICD9 search had a mean score of 1.6 ($n = 107$; 57 positive screens and 50 negative screens). This was significantly different from the mean screener score of 2.4 for all patients with positive screens ($p < 0.001$). Of the 107 patients previously identified by ICD9 search, 21 (19.6 %) had scores of 4 or 5. Patients previously identified by direct physician referral to the clinic case manager had a mean score of 2.7 ($n = 22$; 17 positive screens and 5 negative screens). This was not significantly different than the mean screener score of 2.4 for all patients with positive screens ($p = 0.458$). Of the 22 patients previously identified by direct physician referral, 10 (47.6 %) had a score of 4 or 5.

Discussion

The CSHCN Screener[®] prospectively identified CSHCN in an academic pediatric primary care clinic associated with a tertiary hospital with an overall prevalence rate similar to that reported by the National Survey of CSHCN [3]. This supports previous suggestions that the CSHCN Screener[®] can be used to identify this population of children within an ambulatory setting [24]. However, it is worth noting that the distribution of scores for the population of CSHCN at the study site identified by the screener differs slightly from national data in that the study site had a greater proportion of higher screener scores. Reported national rates for scores of 4 and 5 are 7.0–7.5 and 3.0–3.5 % of all positive screens, respectively [18], while the rates identified for the clinic population in this study were 13.4 and 14.2 % of all positive screens, respectively. This is not unexpected since children with higher screener scores have been shown to have higher rates of health care service utilization [16] and, therefore, are more likely to be identified within the health care system rather than via random phone survey, as was conducted by the National Survey of CSHCN. Further-more, prior research suggests that higher screener scores can be an indicator for severity of disease [25, 26]. Thus, patients with higher screener scores may be more likely to seek care at a primary care clinic within a tertiary medical center where management by multiple pediatric subspecialists in inpatient and outpatient settings is available within the same system of care.

Prevalence rates of CSHCN identified by ICD9 code search in January 2010 and as determined by screener collection in September 2012, 13.8 and 16.8 % respectively, are similar in that they both fall within the published national prevalence rates of CSHCN [2–5]. This suggests that the CSHCN Screener[®] is at least as effective at identifying CSHCN as the previously used method of ICD9 code search. However, the CSHCN Screener[®] offers the advantage of being a prospective process, thereby making it more conducive to use in an ambulatory setting. In addition to its retrospective nature, the method of ICD9 code search has several other limitations. It inherently relies on inconsistent, incomplete, and often inaccurate coding practice, and it will fail to capture patients who have significant special needs but where the diagnosis, and hence a specific ICD9 code, has not yet been designated or does not exist. Furthermore, this type of condition-specific identification does not provide

a straightforward means for stratification of this population, nor does it account for variation in severity of disease or complexity of health care needs among patients with the same diagnosis. For example, a patient with hypoplastic left heart syndrome with several other comorbidities in the midst of staged surgical repair would be expected to have a much higher level of health care needs than a patient with isolated hypoplastic left heart syndrome status post successful repair. The observation that functional limitations vary widely within diagnosis groups is confirmed by the Child and Adolescent Health Measurement Initiative report “2009/10 NS-CSHCN: Prevalence of Specific Difficulties among CSHCN with Each Condition” [27]. The CSHCN Screener[®] overcomes this limitation by utilizing a consequence-based approach with an emphasis on identifying both the functional and service needs of a child rather than simply identifying the presence of a chronic condition or specific diagnosis. The ability to stratify the population of identified CSHCN based on level of required health needs is important because it offers a rubric for allocating limited health care resources that could improve care while reducing overall health care costs for this population (e.g. care coordination services) [28–30]. The value of an identification process with inherent stratification properties is underscored by the fact that the population of CSHCN identified by retrospective ICD9 search who also completed a screener during the study period had lower scores than those CSHCN identified by screener completion alone (mean scores of 1.6 vs. 2.4, p value <0.001), particularly since nearly half of the patients previously identified by ICD9 code search who completed the screener had negative screens.

The population of CSHCN in the clinic identified by direct physician referral to the case manager who also completed screeners during the study period had a higher mean screener score (mean 2.7) than the population of CSHCN identified by retrospective ICD9 code search or screener completion alone, with nearly half having scores of 4 or 5. One explanation for this could be that physician awareness of scarce resources (i.e. case management services) propels them to refer only the most complex patients. Alternatively, physicians may underestimate the complexity of some patients, and therefore, only refer patients with exceedingly complex needs. This tendency could be particularly true of physicians practicing at an academic institution where the patient population, in general, has a higher level of complexity as previously discussed. While direct physician referral to the case manager allows for more consideration of complexity of needs, as perceived by the provider at the point of service, criteria for referral are not standardized across practices or even among physicians within a practice since there is no consensus definition of medical complexity [31]. The CSHCN Screener[®] offers a potential solution to this problem as it provides a structured method for stratification of the population of CSHCN according to their degree of medical complexity.

As with all screening tools, a large number of patients without special health care needs must complete the CSHCN Screener[®] in order to identify the small proportion of CSHCN. While this type of screening process is standard practice within general pediatrics (i.e. recommended developmental screening tools), the cost of implementing use of the CSHCN Screener[®] must be considered. Although the screener is only a one page document consisting of five questions, the time needed for completion would compete with other demands on the families' time. Personnel and supply costs associated with copying, distributing, and scoring the screener should also be considered. However, these costs should

be weighed against those associated with other methods of CSHCN identification. For example, ICD9 searches for an entire clinic population remain labor intensive and time consuming, even if utilizing an electronic medical record. Thus, the frequency with which this method can be completed is limited. Given that ICD9 search is a retrospective process, limiting the frequency of updates inhibits effectiveness of any intervention for that identified population. Nonetheless, use of ICD9 codes for identification of CSHCN may remain a more practical approach in certain settings. Physician referrals to the case manager requires little administrative manpower and physician effort, but without standardized referral criteria comparison across institutions will not be feasible. Furthermore, inappropriate referrals will limit the efficiency of case management services for the overall population of CSHCN within the clinic. It is worth noting one additional method for identification and stratification of CSHCN, Clinical Risk Groups assigned by 3M Health Information Services software according to presence, type, and severity of chronic conditions as determined by prior hospital encounters [32–34]. While this method offers a means for stratification based upon level of medical complexity, it is less suited for identification of an outpatient cohort of CSHCN due to its reliance on inpatient billing data. In conclusion, the chosen method for identification of CSHCN in an ambulatory setting will depend on the recognized purpose for identification and available resources. Furthermore, use of the varying strategies for identification and stratification of this population in a complementary fashion, or hybrid approach, may prove to be most beneficial.

This study has several limitations. Most notably, the various registries were generated at different but overlap-ping time points (January 2010 through September 2012) and the transience of our general clinic population, as well as our population of CSHCN, is high. Therefore, direct comparisons between groups to calculate positive predictive values could not be completed since the initial method of ICD9 search could not capture patients born after January 2010, nor could it capture new patients joining the practice or acquiring a new chronic condition after this time. Comparison with the direct physician referral cohort was not feasible either, as this cohort was collected up until September 5, 2012. This limitation is confounded too by the lack of a defined gold standard for identification and stratification of CSHCN. Furthermore, a child's health status is not a linear process, and in many cases the status of having a special health care need is transient. In other words, a child can move “in and out” of the CSHCN definition over time. Likewise, his/her degree of medical complexity within that definition can also change over time. The lack of a gold standard method for identification and stratification of CSHCN and the transient nature of a child's health status are methodological barriers for research involving CSHCN unless child-level data can be obtained.

The return rate of 63 % for screeners in the study, while adequate for data analysis, is not ideal for true clinical application and is a lower rate than that reported from national self-assessment data for the screener [16]. In addition, 14 % of returned screeners had to be excluded due to being incomplete or illegible; this was due to the fact that all screeners were self-administered by patient families. Barriers to distribution, collection, and completion of the screener were not formally assessed. Barriers could include system-level factors such as variation in the processes for distribution and collection of the screeners, poor formatting of the screening tool, or limited office time and/or competing demands for time (both of staff

and patients/families). Population-specific factors may also be contributing to these rates, such as low literacy and numeracy levels of the clinic population, as well as language barriers and cultural barriers that are likely prevalent given the diverse ethnicities of the clinic population. Prior research supports the potential presence of language and cultural issues when identifying CSHCN, specifically for the Hispanic population [35]. Lastly, patients who were motivated to complete and return the screener may not be representative of the general population of clinic patients nor the overall population of CSHCN in the clinic.

It is important to design improved systems of care for CSHCN that promote overall health and well-being for patients and families, as well as decrease costs through prevention of avoidable hospital admissions, prolonged hospital stays, and unnecessary emergency room visits. A clinically meaningful and practical method for identification and stratification of CSHCN within an ambulatory setting is needed. This study shows that the CSHCN Screener[®] can be utilized in an academic primary care clinic to prospectively identify CSHCN and provides a means for stratification of this population based on complexity of medical needs. It potentially offers an alternative method for identification and stratification of CSHCN, or may be used synergistically with previously used methods such as retrospective ICD9 code search and direct physician referral to a clinic case manager. Future work will need to focus on obtaining child-level data at the time of screener completion in order to facilitate direct comparison between these various methods of identification and stratification of CSHCN. If the CSHCN Screener[®] proves to be a sensitive and specific means for identifying this population, additional work will need to focus on improving processes for its implementation within an ambulatory setting.

Acknowledgments

We thank Dr. Christina Bethell for permitting use of the CSHCN Screener[®] and for her willingness to provide guidance regarding its implementation in an ambulatory setting. Salary support and protected scholarly time was provided to the principal investigator through the Katherine Dodd Faculty Scholars Program of the Vanderbilt University Department of Pediatrics. Funding for the development of the REDCap database was provided to the study site's institution via NIH Grant # UL1TR000445.

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Children with Special Health Care Needs (CSHCN) Screener[®] (mail or telephone)

1. Does your child currently need or use medicine prescribed by a doctor (other than vitamins)?
 - ☐ Yes → Go to Question 1a
 - ☐ No → Go to Question 2
 - 1a. Is this because of ANY medical, behavioral or other health condition?
 - ☐ Yes → Go to Question 1b
 - ☐ No → Go to Question 2
 - 1b. Is this a condition that has lasted or is expected to last for at least 12 months?
 - ☐ Yes
 - ☐ No
2. Does your child need or use more medical care, mental health or educational services than is usual for most children of the same age?
 - ☐ Yes → Go to Question 2a
 - ☐ No → Go to Question 3
 - 2a. Is this because of ANY medical, behavioral or other health condition?
 - ☐ Yes → Go to Question 2b
 - ☐ No → Go to Question 3
 - 2b. Is this a condition that has lasted or is expected to last for at least 12 months?
 - ☐ Yes
 - ☐ No
3. Is your child limited or prevented in any way in his or her ability to do the things most children of the same age can do?
 - ☐ Yes → Go to Question 3a
 - ☐ No → Go to Question 4
 - 3a. Is this because of ANY medical, behavioral or other health condition?
 - ☐ Yes → Go to Question 3b
 - ☐ No → Go to Question 4
 - 3b. Is this a condition that has lasted or is expected to last for at least 12 months?
 - ☐ Yes
 - ☐ No
4. Does your child need or get special therapy, such as physical, occupational or speech therapy?
 - ☐ Yes → Go to Question 4a
 - ☐ No → Go to Question 5
 - 4a. Is this because of ANY medical, behavioral or other health condition?
 - ☐ Yes → Go to Question 4b
 - ☐ No → Go to Question 5
 - 4b. Is this a condition that has lasted or is expected to last for at least 12 months?
 - ☐ Yes
 - ☐ No
5. Does your child have any kind of emotional, developmental or behavioral problem for which he or she needs or gets treatment or counseling?
 - ☐ Yes → Go to Question 5a
 - ☐ No
 - 5a. Has this problem lasted or is it expected to last for at least 12 months?
 - ☐ Yes
 - ☐ No

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Fig. 1.
Copy of Children with Special Health Care Needs Screener[®]

Fig. 2.
Flow diagram of screener collection results

Table 1

Demographic characteristics of patients with completed screeners

	All counted screeners (n = 1,467)	Positive screeners (scores 1–5) (n = 246)	Negative scr eeners (score 0) (n = 1,221)	<i>p</i> value*
Age (year)				
Mean (SD)	4.1 (3.981)	6.6 (3.819)	3.6 (3.818)	<0.001
Age group				
<2 years old, % (n)	44.7 (656)	12.6 (31)	51.2 (625)	<0.001
2 years old, % (n)	55.3 (811)	87.4 (215)	48.8 (596)	
Sex				
Male, % (n)	51.5 (755)	65.9 (162)	48.6 (593)	<0.001
Female, % (n)	48.5 (712)	34.1 (84)	51.4 (628)	
Race/ethnicity				
Black, % (n)	40.2 (590)	47.2 (116)	38.8 (474)	
Hispanic, % (n)	28.1 (412)	16.7 (41)	30.4 (371)	
White, % (n)	23.2 (341)	29.7 (73)	21.9 (268)	<0.001
Other/unknown, % (n)	8.5 (124)	6.5 (16)	8.8 (108)	
Screeners language				
English, % (n)	74.2 (1,089)	86.6 (213)	71.7 (876)	<0.001
Spanish, % (n)	21.3 (313)	12.2 (30)	23.2 (283)	
Arabic, % (n)	4.4 (65)	1.2 (3)	5.1 (62)	
Insurance				
Medicaid, % (n)	81.3 (1,192)	84.6 (208)	80.6 (984)	
Commercial, % (n)	14 (205)	13.4 (33)	14.1 (172)	0.078
Other/none, % (n)	4.8 (70)	2.0 (5)	5.3 (65)	

*
p value determined by Chi square test for categorical variables; Two-sample *t* test for continuous variables