Identification of Children With Special Health Care Needs Within a Managed Care Setting

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Objective: To assess 2 established methods of identifying children with special health care needs (CSHCN) within a health plan population for intensified service coordination.

Methods: The tools tested were the Questionnaire for Identifying Children With Chronic Conditions (QuICCC) and the Clinical Risk Grouper (CRG) software. The QuICCC was administered by telephone to the parents of 517 children. The CRG software tool was then applied to the health plan database. The accuracy of identifying the target population was assessed by a single trained reviewer by comparison with the comprehensive medical record.

Results: According to the QuICCC, 37.1% of the parents surveyed had CSHCN. According to the CRG, 11% of the health plan’s pediatric population was categorized as CSHCN. The medical record review agreed with overall QuICCC findings in 53% to 61% of cases and overall CRG findings in 66% to 73% of cases.

Conclusions: Administering the QuICCC was a time- and labor-intensive endeavor with a relatively low overall level of sensitivity. The CRG was less labor intensive with slightly higher sensitivity. Identifying the target population in an effective and efficient manner remains a challenge for health plans.


A definition and identification advisory committee to the SAFE at Home Project, composed of community experts in the target population or in identification methods, was established. This group examined a number of available tools to assess their strengths, weaknesses, and applicability to the project goals. Tools considered included the classification of congenital and chronic health conditions, the disability payment system, the operational criteria for identifying disabled persons using MMISII (Medicaid Management Information System) data, the Questionnaire for Identifying Children With Chronic Conditions (QuICCC), and the Clinical Risk Grouper (CRG) software (3M Health Information Systems, Murray, Utah).

Based on the committee’s input, the QuICCC and the CRG software were identified as viable options for identifying CSHCN within a managed care population.
tion. The committee and the project staff believed that the QuICCC survey tool could capture the broadest population and would have the benefit of incorporating parental perceptions, whereas the CRG software could capture a more targeted population based on available electronic data. Although neither tool was originally designed for the purpose of identifying children within a health plan for intensified service coordination, each tool was thought to have its own advantages, particularly in terms of yielding the most accurate and useful capture and being most feasible for use by the health plan in this type of effort. HealthPartners agreed to test both of the tools selected. The goal of this practical exercise was not to conduct a direct comparison between the 2 approaches to case identification but to assess how well each tool would individually identify CSHCN for intensified service coordination and how feasible each approach might be for ongoing implementation by the health plan.

THE INSTRUMENTS

The QuICCC

The QuICCC was developed and copyrighted by Stein et al in 1997 to operationalize a noncategorical definition of chronic conditions. The 39-item interview tool asks questions of parents about various aspects of their child’s functional ability and limitations, service use, and reliance on compensatory mechanisms. The QuICCC is a validated scale that defines CSHCN to include those with (1) a disorder that has a biological, psychological, or cognitive basis that (2) has lasted or is virtually certain to last for at least 1 year and (3) produces limitation of function, dependence on compensatory mechanisms, and need for related ancillary services. The tool is not based on specific diagnoses but rather focuses on the consequences of special health conditions and was designed for epidemiologic purposes.

Permission to administer the QuICCC was obtained from its developers in September 1999. Interviews were conducted using the QuICCC survey with a sample population of parents of children between the ages of 3 and 12 years, the age group that was of most interest to our practitioners. Originally, it was thought that clinic staff could conduct 250 face-to-face surveys, with research foundation staff conducting 250 telephone surveys from a centralized site, to reach a target of 500 interviews. Because of time and staffing constraints at the clinics and despite a financial incentive, clinic staff members were unable to conduct any surveys; therefore, all surveys were ultimately conducted via telephone through the research foundation.

From the HealthPartners encounter database, a random sample of children between the ages of 3 and 12 years who had been seen at 1 of 3 of the health plan’s clinics between September 1 and November 30, 1999, was generated. The clinics selected were those with the greatest number of pediatric patients. One thousand names were chosen to ensure a final sample size of 500 completed interviews. Letters were sent to the parents of all children on the list to inform them of the purpose of the study and to let them know that they might be contacted for an interview. Parents were given the option of refusing to participate and the opportunity to let the interviewers know the best time to reach them by either calling the research foundation or returning a postage-prepaid reply card that was included with the letter.

Telephone interviewers received training and practice using the QuICCC and were instructed to complete a cover sheet documenting the interview for each respondent. Interviewers were instructed to make at least 3 call attempts at various times throughout the day before declaring the subject “unreachable.” Telephone interviewers documented the start and stop time of each interview and made note of any specific diagnoses mentioned during the conversation. A total of 517 interviews were conducted.

The CRG

3M Health Information Systems and the National Association of Children’s Hospitals and Related Institutions (NACHRI), Alexandria, Va, developed the CRG software in 1999 and released it to the public in 2000. The CRG is a population-based classification system that uses diagnostic information from claims and encounter databases and assigns each patient to a single, mutually exclusive clinical risk category and severity level. The CRG is based on a premise similar to diagnosis-related groups in that it provides a classification system for individual characteristics and service use; however, the CRG was designed to predict future resource use. The CRG uses an operational definition of chronic health condition that incorporates 3 elements: (1) physical, mental, emotional, behavior, or developmental disorder; (2) expected to last at least 12 months or longer or having sequelae that last at least 12 months or longer; and (3) requires ongoing treatment and/or monitoring. The CRG was designed for use by health plans and communities as they address population-level health issues.

At the start of our project, the CRG software had not yet been released to the public. In May 2000, HealthPartners Research Foundation entered into a research agreement with 3M Health Information Systems that allowed us to test the software before marketing. Originally, HealthPartners agreed to provide a data file to 3M Health Information Systems to enable them to run the software for the health plan as part of their beta testing process, but because of timing and staff constraints within 3M, HealthPartners ultimately ran the software in-house.

HealthPartners has a claims-based data system that contains demographic, membership, and utilization information on each member. HealthPartners claims and encounter databases were used to gather the required data elements for members who were between the ages of 3 and 12 years and had as their primary clinic designation 1 of the same 5 clinics that were used for the QuICCC interviews. A combination of utilization
Table 1. Distribution of Random Medical Record Review Results by Number of Questions Answered Yes on the Questionnaire for Identifying Children With Chronic Conditions

<table>
<thead>
<tr>
<th>No. of Questions Answered</th>
<th>Medical Record Review</th>
<th>Total No. of Records</th>
<th>Agreement Range, %</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Agreed</td>
<td>Disagreed</td>
<td>Inconclusive</td>
</tr>
<tr>
<td>1</td>
<td>10</td>
<td>16</td>
<td>1</td>
</tr>
<tr>
<td>2</td>
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</tr>
<tr>
<td>3</td>
<td>3</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>&gt;3</td>
<td>20</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td>43</td>
<td>32</td>
<td>6</td>
</tr>
</tbody>
</table>

*Low end of range represents including “inconclusive” with “disagreement”; high end of range, including “inconclusive” with “agreement.”

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CRG categorized 386 (4% of the total pediatric health plan population) in the single minor chronic disease group and 572 (nearly 6%) of the total pediatric health plan population) in the single dominant or moderate chronic disease group (Table 2).

Of the sample of medical records reviewed for those identified by CRG (n=125), overall 66% to 73% were in agreement with core health status group 5 (single dominant or moderate chronic disease), having an agreement rate of 77% to 87%. Medical record review confirmed CSHCN status of the 1 child in core health status group 6 (significant chronic disease in multiple organ systems). 1 of 2 children identified in core health status group 8 (dominant, metastatic, and complicated malignancies), and all 10 children identified in core health status group 9 (catastrophic conditions) (Table 3).

Forty-six children were identified as CSHCN by both tools, and we were able to locate and review complete records for 43 children in this group. The medical record review indicated agreement for 30 to 33 (70%-77%) of these cases. Twenty-five (58%) fell into CRG core health status group 5 (single dominant or moderate chronic disease); 11 (25%) answered “yes” to only 1 QuICCC question, whereas 16 (37%) answered “yes” to 4 or more questions.

Of the 21 complete records reviewed for children not identified as CSHCN by either tool, 18 to 19 (86%-90%) agreed with the tools’ assessment of no special health care need. In 2 cases, the record review indicated a special health care need, although the tools did not, and in 1 case, the record review was inconclusive.

Identifying CSHCN continues to be a challenging task. The 2 tools selected for this project were well-researched and tested instruments that were thought to be usable and useful for health plans. In reports about the QuICCC, developers Stein and colleagues report that validity and reliability for epidemiologic and research purposes have been established for their tool, with further testing showing 94% sensitivity, 83% specificity, 86% positive predictive value, and 92% negative predictive value.6 The CRG is built on NACHRI’s classification of congenital and chronic health conditions and a similar population-based classification system product developed by 3M Health Information Systems and has been reported to do a good job of identifying CSHCN, particularly those with conditions requiring frequent interaction with the health care system.8 Our experience, however, did not reflect similar overall sensitivity except for children with 3 or more “yes” responses to the QuICCC or for children in core health status groups 5, 6, or 9 using the CRG.

For a child who is truly in the target population of those having a special health care need who would benefit from intensified service coordination, we would expect at least some indication and/or verification of the situation in their medical record. HealthPartners has extensive and detailed medical records for each member of the health plan. All clinic visits, laboratory services, referrals, and hospitalizations are documented, as well as notations about mental, social, and educational needs. Therefore, we compared the results of medical record review to the findings of the tools, and the results were rather unexpected, with 25% to 30% of the children identified as CSHCN by both tools showing no special health care need in their medical record. Individually, each tool provided results with even less agreement with medical records. We would have expected a higher rate of agreement between the medical record and the tools to identify CSHCN.

Although the tools tested in this study are appealing conceptually, implementing them presented considerable challenges. The QuICCC was time and labor-intensive. It is designed to capture a broad segment of the population and does not provide a stratification system based on severity. This seemed to make the results somewhat unreliable. Although the developers suggest that 1 “yes” answer should trigger concern, the QuICCC seemed to be most reliable (87%-96%) for those chil-
children whose parents answered “yes” to more than 3 questions. In our study, the instrument’s overall lack of accuracy in identifying CSHCN patients (53% in clear agreement and up to 61% if we assume that all “inconclusive” cases would be found to have a special health care need) makes it unlikely to be adopted by a health plan based on 1 “yes” response. We could only consider using this instrument as a vehicle for identifying children to bring to the attention of physicians for enhanced “medical home” services, such as intensified service coordination for those individuals with 3 or more “yes” responses.

Although some may have concerns about the use of interview techniques in terms of confidentiality and parental perceptions of the risks and benefits of CSHCN identification in terms of future services, our sample of parents did not seem to underreport special health care needs; in fact, the percentage with special health care needs was much greater than expected. Since parents of children with special needs often assume the role of advocate for their child, we believe it is unlikely that they would underreport their child’s need for services. Furthermore, parents would have little motivation to overreport, since our system is capitated with set benefit packages; therefore, their children can be seen as often as they wish with minimal copayments.

Unfortunately, although we were able to implement the QuICCC through the health plan’s research foundation under the auspices of this grant, clinical personnel were unable or unwilling to add this to their workload. Many health plans do not have a centralized research entity to facilitate implementation. It is unlikely that a health plan would be able to devote ongoing resources to this method of identification, especially when the results did not attain the desired level of sensitivity. Stein et al10 and Bethel et al11 studied whether shorter tools to identify CSHCN would yield results as accurate as the assessment of the original QuICCC. These authors found that the shorter version of the QuICCC, which is composed of 16 questions (the QuICCC-R), and the CSHCN Screener could be used as acceptable alternatives for screening purposes. Although these abbreviated tools have the potential for being more feasible for implementation in a health plan such as ours, we would need to examine the rate of accuracy for these instruments within our health plan to determine if they would be likely to be useful. Although others may now be using these shorter tools as the primary means to screen for CSHCN within a clinical setting, we believe this exercise of examining the ability of the QuICCC to identify CSHCN within a managed health plan is worthwhile because the longer tool may still be used for epidemiologic purposes.

When we tested the CRG, it required a much larger amount of up-front learning time to understand and install the software than we expected based on our conversations with the developers. Now that the product has been released to the public, some of the glitches that we encountered may have been minimized. The most reliable CRG categories were those with extremely severe conditions, such as core health status group 6 “single chronic disease in multiple organ systems” and core health status group 9 “catastrophic conditions,” with core health status group 5 “single dominant or moderate chronic disease in multiple organ systems” and core health conditions, such as core health status group 6 “single able CRG categories were those with extremely severe

Finally, our medical record abstraction checklist created by our specialist in developmental pediatrics was not a standardized or validated tool. The tool was designed specifically for this exercise to identify children who should be brought to the attention of a practitioner for
possible intensified service coordination. Although our medical records are of excellent quality and provide a comprehensive view of all health plan coverage, they may not capture all services provided outside the health plan. Nonetheless, we believe this potential limitation of our medical records would affect few children covered by the health plan and have minimal impact on our overall findings. Furthermore, although there may be a certain amount of subjectivity involved in making interpretations from medical records, all cases in which there was any question of CSHCN status by the abstractor were also reviewed by our pediatric expert.

CONCLUSIONS

Identifying CSHCN remains an important area for health care practitioners. Ensuring the provision of needed services and linking families with appropriate available resources through intensified service coordination can make a difference in the quality of life of these children. The challenge still remains, however, whether screening approaches with adequate sensitivity and specificity can be found to assist practitioners in identifying these individuals in an effective and efficient manner.

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