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ORIGINAL ARTICLES

Health Services and Health Care Needs Fulfilled by Structured Clinical Programs for Children with Medical Complexity

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Objective To describe family-reported health service needs of children with medical complexity (CMC) and to assess which needs are more often addressed in a tertiary care center-based structured clinical program for CMC.

Study design Mailed survey to families of CMC enrolled in a structured-care program providing care coordination and oversight at 1 of 3 children's hospitals. Outcomes included receipt of 14 specific health service needs. Paired *t* tests compared unmet health care needs prior to and following program enrollment.

Results Four hundred forty-one of 968 (46%) surveys were returned and analyzed. Respondents reported their children had a mean age of 7 (SD 5) years. A majority of respondents reported the child had developmental delay (79%) and feeding difficulties (64%). Of the respondents, 56% regarded the primary care provider as the primary point of contact for medical issues. Respondents reported an increase in meeting all 14 health services needs after enrollment in a tertiary care center-based structured clinical program, including primary care checkups (82% vs 96%), therapies (78% vs 91%), mental health care (34% vs 58%), respite care (56% vs 75%), and referrals (51% vs 83%) (all $P < .001$).

Conclusions Tertiary care center-based structured clinical care programs for CMC may address and fulfill a broad range of health service needs that are not met in the primary care setting. *(J Pediatr 2016;169:291-6)*.

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Children with special health care needs (CSHCN) "have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and require health and related services of a type or amount beyond that required by children generally."[1] Of specific interest among CSHCN are children with medical complexity (CMC): the most medically fragile and the highest resource utilizers of all CSHCN because of multiple subspecialty care needs, functional limitations, and medical technology needs.[2] The prevalence of CMC is rising in large part because of increasing premature and low weight births, advances in surgical and intensive care, and increased use of medical technology to maintain health and functioning.[3]

CMC require a high level of health care and supportive services that families report are frequently not met, such as preventive care, oral health care, access to specialty care, mental health care, transition of care services, and care coordination.[4-7] Almost one-half (48.8%) of families of CMC report ≥1 unmet health care need, and 5.4% report ≥5 unmet needs.[8] The high level of unmet needs occurs across all races/ethnicities, incomes, or insurance types of the child.[9] Families of CMC report inadequate access to the pediatric subspecialty and mental health care providers that could mitigate the high level of unmet health care needs.[10-14]

Community-based primary care physicians (PCPs) report limited capacity to care for CMC.[15,16] Dedicated tertiary care center-based structured clinical programs for CMC at children's hospitals have emerged to meet the need for care management and coordination. These programs typically provide dedicated care coordinators, co-location of specialists, or a multidisciplinary team that address growth and nutrition, medical technology management, and access to appropriate care.[2,17-22] Their location in tertiary care centers where CMC frequently access services[2,18,20] may enable the necessary intensive and effective care coordination and case management.[17,19-21] Cost savings of the programs because of reduction of preventable inpatient and emergency department visits have been described.[20,22-24] Specific health service needs of families of CMC

CMC	Children with medical complexity
CSHCN	Children with special health care needs
NS-CSHCN	National Survey of CSHCN
PCP	Primary care physician

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Portions of the study were presented at the meeting of the Pediatric Academic Societies, Vancouver, BC, Canada, May 3-6, 2014, as well as at the meeting of the American Academy for Cerebral Palsy and Developmental Medicine, San Diego, CA, September 10-13, 2014.

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who attend such programs, however, have not previously been described, particularly after enrollment in these programs.

The objectives of this study were to describe the family-reported health service needs of CMC enrolled in a tertiary-based structured clinical care program, and to determine the extent to which needs are addressed by programs for CMC.

Methods

This study is a multisite survey of families of children currently enrolled in structured, comprehensive care programs for CMC at 3 tertiary care children's hospitals: Medical Home Clinic, Arkansas Children's Hospital; Special Needs Program, Children's Hospital of Wisconsin; and Complex Care Service, Boston Children's Hospital. The programs were identified as relatively mature structured complex care programs, with each program in existence for at least 8 years prior to the survey. Each program is consultative, with all patients continuing to have a local PCP. Common enrollment criteria included the presence of multiple chronic conditions requiring care from multiple specialists. The study sample was limited to children who were currently enrolled in one of the programs.

Study enrollment criteria included all families of CMC who were currently enrolled in each clinical program and had been enrolled in the prior 5 years. Prior analyses from the National Survey of CSHCN (NS-CSHCN) suggest that almost 50% of CMC have at least one unmet medical service need, and 20% of non-CMC have ≥1 unmet medical service need.[9] Based on a power of .8 and a 2-tailed alpha of .05, assuming equal sample sizes, a difference of ≥1 unmet needs of 50% vs 35% would require a total sample size of 366. We assumed a 50% return rate.

The study protocol was approved separately by Institutional Review Boards at the University of Arkansas for Medical Sciences, Children's Hospital of Wisconsin, and Boston Children's Hospital. Following the individual requirements of the Institutional Review Boards, the surveys for children at Arkansas and Wisconsin were mailed from and returned to research staff at Arkansas. Surveys for Boston Children's Hospital were mailed from and returned directly to Boston, with de-identified data shared to study investigators based in Arkansas. Prior to mailing, the survey was piloted with 5 families at Arkansas Children's Hospital, with revisions made from feedback on clarity and readability. We verified that the survey took less than 10 minutes to complete. Surveys were mailed out with reminders to encourage survey completion using a modified Dillman approach.[25] The initial survey was mailed with a $1 bill as an incentive to complete the survey.

The survey content was developed by adapting questions used in the 2009-10 NS-CSHCN. This survey provides prevalence estimates of CSHCN and a description of services utilized by CSHCN and their families, as well as detailed aspects of health care utilization, health status, and family burden.[26] The NS-CSHCN is conducted annually by the National Center for Health Statistics and uses a computer-assisted telephone interview on a national random population sample.[26] The survey was administered in English only. The survey had 2 main outcomes: primary care and met/unmet needs. Families were asked whether they received specific services by the primary care provider in the prior 12 months. Specific services included receipt of well child care; chronic illness management, such as care planning and referrals; and nutritional support. Families were asked about 14 specific health service needs (**Figure**; available at www.jpeds.com) that were adapted from the NS-CSHCN for a written, paper survey format. For each health service need, respondents were asked if the child had an unmet need upon enrollment in the comprehensive care program and during the 12 months after enrollment. A child was considered to have a met need if the respondent indicated that there was a need and that need was met. An aggregate variable of unmet needs was calculated by adding the number of unmet needs indicated per child.

Descriptive variables included the age and race/ethnicity of the child, and the age of the responding parent caregiver. Clinical conditions were assessed by survey response to describe parental perception of health care diagnoses and needs. The health and functional status of the child was subjectively described by the respondent's assessment of the functional level of the child, need for specific technology, the number and type of specialists seen, and hospital and emergency department use in the prior year. Families were asked about the number of hours families spent per week on care coordination and direct home care, as well as the out of pocket financial costs in the last year, using questions adapted from the NS-CSHCN. Categorical variables were selected to ease survey administration.

Data Analyses

Descriptive demographic statistics were compiled from the raw data. Bivariate analyses were performed with *t* tests for continuous variables and χ^2 for categorical variables. A comparison of health care services received before and after enrollment in the comprehensive care program was accomplished using paired *t* tests. Some variables had missing data, but generally the missing data were 2% or less; because of this low percentage, subjects with missing data were excluded. Study findings of health care services were similar between all 3 services and, hence, are presented in the aggregate. All analyses were conducted using Stata 12.0 (StataCorp, College Station, Texas).

Results

Of 968 mailed surveys, 441 (46%) were completed and returned. The survey response rates were 43% (n = 140) for Boston families, 46% (n = 201) for Arkansas families, and 50% (n = 100) for Wisconsin families. The characteristics