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Original Research

Care coordination, medical complexity, and unmet need for prescription medications among children with special health care needs

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Abstract

Background: Children with special health care needs (CSHCN) have multiple unmet health care needs including that of prescription medications.
Objectives: The objectives of this study were twofold: 1) to quantify and compare unmet needs for prescription medications for subgroups of CSHCN without and with medical complexity (CMC)—those who have multiple, chronic, and complex medical conditions associated with severe functional limitations and high utilization of health care resources, and 2) to describe its association with receipt of effective care coordination services and level of medical complexity.
Method: A secondary data analysis of the 2009/2010 National Survey of CSHCN, a nationally representative telephone survey of parents of CSHCN, was conducted. Logistic regression models were constructed to determine associations between unmet need for prescription medications and medical complexity and care coordination for families of CSHCN, while controlling for demographic variables such as race, insurance, education level, and household income. Analyses accounted for the complex survey design and sampling weights.
Results: CMC represented about 3% of CSHCN. CMC parents reported significantly more unmet need for prescription medications and care coordination (4%, 68%), compared to Non-CMC parents (2%, 40%). Greater unmet need for prescription medications was associated with unmet care coordination (adjusted OR 3.81; 95% CI: 2.70–5.40) and greater medical complexity (adjusted OR 2.01; 95% CI: 1.00–4.03).
Conclusions: Traditional care coordination is primarily facilitated by nurses and nurse practitioners with little formal training in medication management. However, pharmacists are rarely part of the CSHCN care coordination model. As care delivery models for these children evolve, and given the complexity of and numerous transitions of care for these patients, pharmacists can play an integral role to improve unmet needs for prescription medications.

Keywords: Children with medical complexity; Care coordination; Prescription medications; Unmet health care needs

Conflicts of interest: None to report.
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Introduction

Families of children with special health care needs (CSHCN)—those representing about 15% (or nearly 12 million) of U.S. children under the age of 18[1]— report multiple unmet health care and social needs.[2] The Maternal and Child Health Bureau (MCHB) of the Health Services and Resources Administration defines CSHCN as those "who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health related services of a type or amount beyond that required by children generally."[3] Recently, a subset of CSHCN with more complex medical conditions, referred to as children with medical complexity (CMC) has received increased attention from researchers and policymakers. CMC represent the most medically fragile group of children and are characterized by multiple chronic and severe medical conditions that are associated with severe functional limitations and high health care resource utilization.[4] Despite representing just less than 1% of all U.S children, it is estimated that CMC account for as much as one-third of health care spending for all children.[5]

The sphere of care for CSHCN is extensive, and as a result, they often receive care that is fragmented and poorly coordinated resulting in family stress, unsafe care, and suboptimal health outcomes.[6] Families of such children also report lacking information and quality communication as well as difficulty navigating the health care system.[7]

Prescription medications play a central role in the overall treatment plan for CSHCN. This is especially true for the CMC subset of CSHCN, as these children are likely to receive numerous medications for the multiple chronic conditions they live with. Stone and colleagues, for example, reported that CMC take an average of at least 8 chronic medications.[8] Factors related to medical conditions of the child, the delivery of health care services, as well as the social circumstances of families of CSHCN may play a key role in determining whether CSHCN have their needs met for prescription medications.

While some studies have previously examined unmet health care needs—such as specialty[2] and dental care[9]—for CSHCN, to our knowledge, no study has specifically examined unmet needs for prescription medications for this patient population. Thus, the objectives of this study were to describe unmet prescription medication needs for CSHCN based on medical complexity as well as determine potential predictors of unmet prescription medication needs using data from a nationally representative survey of CSHCN.

Methods

Data source

This study is a secondary analysis using data from the 2009/2010 National Survey of CSHCN (NS–CSHCN). The NS-CSHCN is a nationally representative telephone survey of U.S. households that have at least one child under 18 years at the time of the interview. During data collection, an interviewer screened all children in the household for having special health care needs using a five-item instrument. If more than 1 CSHCN were identified in the household, one CSHCN was randomly chosen for the interview. Then, a parent or guardian with the most knowledge about the health and health care needs of the child in the household was asked a series of questions addressing various aspects of health and social care for the child including health and functional status, need and receipt of health care and social services, and impact of child's health conditions on the wellbeing of family members. At the conclusion of data collection, 40,242 CSHCN interviews were completed representing at least 750 CSHCN from each state of the U.S.

Study sample

Multiple criteria are used to define children with medical complexity. Many structured clinical programs in U.S. children hospitals utilize criteria for enrollment based on family identified service needs, dependence on medical technology to support daily life and functioning, and involvement of multiple specialists in the care of the child. Kuo and colleagues utilized such criteria to identify CMC from the NS-CSHCN and their studies served as the basis for categorizing CSHCN based on presence or absence of medical complexity.[10,11] To be considered as having a complex medical condition, a child must meet the following criteria: 1) a positive response to the CSHCN screener question indicating need or use of medical care, mental health or educational services than is usual for most children of the same age; 2) a positive response to at least 3 of the remaining 4 CSHCN screener questions (i.e. need for prescribed medicines; functional limitation; need for physical occupational, or speech therapy; and presence of