



# Improving the Quality of Home Health Care for Children With Medical Complexity

Savithri Nageswaran, MD, MPH; Shannon L. Golden, MA

From the Department of Pediatrics, Wake Forest School of Medicine, Winston-Salem, NC

Conflict of Interest: The authors declare that they have no conflict of interest.

Address correspondence to Savithri Nageswaran, MD, MPH, Department of Pediatrics, Wake Forest School of Medicine, 1 Medical Center Blvd, Winston-Salem, NC 27157 (e-mail: [snageswa@wakehealth.edu](mailto:snageswa@wakehealth.edu)).

Received for publication October 27, 2016; accepted April 17, 2017.

## ABSTRACT

**OBJECTIVE:** The objectives of this study are to describe the quality of home health care services for children with medical complexity, identify barriers to delivering optimal home health care, and discuss potential solutions to improve home health care delivery.

**METHODS:** In this qualitative study, we conducted 20 semi-structured in-depth interviews with primary caregivers of children with medical complexity, and 4 focus groups with 18 home health nurses. During an iterative analysis process, we identified themes related to quality of home health care.

**RESULTS:** There is substantial variability between home health nurses in the delivery of home health care to children. Lack of skills in nurses is common and has serious negative health consequences for children with medical complexity, including hospitalizations, emergency room visits, and need for medical procedures. Inadequate home health care also contributes to caregiver burden. A major barrier to delivering optimal home health care is the lack of training of home health nurses in pedi-

atric care and technology use. Potential solutions for improving care include home health agencies training nurses in the care of children with medical complexity, support for nurses in clinical problem solving, and reimbursement for training nurses in pediatric home care. Caregiver-level interventions includes preparation of caregivers about: providing medical care for their children at home and addressing problems with home health care services.

**CONCLUSIONS:** There are problems in the quality of home health care delivered to children with medical complexity. Training nurses in the care of children with medical complexity and preparing caregivers about home care could improve home health care quality.

**KEYWORDS:** children; home health; medical complexity; quality of care

**ACADEMIC PEDIATRICS** 2017;17:665–671

## WHAT'S NEW

Research about home health care services for children with medical complexity (CMC) is limited. This study sheds light on the quality of home health care services for CMC in the United States and identifies potential strategies to improve home health quality.

CHILDREN WITH MEDICAL COMPLEXITY (CMC) are a group of children with a broad range of medical conditions that often involves multiple organ systems.<sup>1</sup> Although CMC constitute a tiny proportion of children, they contribute to a large proportion of health care utilization and expenditure of all children.<sup>2–4</sup> CMC receive care from multiple health care providers and services for a prolonged period of time.<sup>1</sup> Home health care is one of the important services for CMC in the community.

In the United States, more than 600,000 children receive home health services.<sup>5</sup> The demand for pediatric home health care has increased,<sup>6</sup> and approximately 2% of health

care expenditure for CMC is spent on home health care.<sup>3</sup> Home health care is considered to increase the value of health care delivery by providing good-quality care at home and avoiding care in more expensive hospital settings. There is recent interest in improving the quality of home health care for the adult population in the United States.<sup>7,8</sup> The American Academy of Pediatrics recommends provision of home health services for children by appropriately licensed and pediatric-trained personnel.<sup>6</sup> However, there is limited research focused on home health care services for children and a knowledge gap on the quality of home health care services received by children.

In our qualitative study of the perspectives of caregivers of CMC and home health nurses (HHN) about home health care for CMC, themes regarding quality of home health nursing for CMC emerged. We sought to explore these themes further. Here we describe the quality of home health care delivered to CMC, and identify barriers and potential solutions to improving home health care quality.

## METHODS

This qualitative study was approved by the institutional review board of Wake Forest University Health Sciences (WFUHS) and conducted at Brenner Children's Hospital, a tertiary-care children's hospital within WFUHS in northwestern North Carolina. Our methodology has been previously described in detail.<sup>9</sup>

### DATA COLLECTION

Data include interviews of caregivers of CMC and focus groups of HHN about home care of CMC, participant surveys, and information obtained from medical record review about children's needs for technology assistance and health insurance. Signed informed consent was obtained from and a \$25 incentive provided to participants.

### CAREGIVER INTERVIEWS

Using purposive sampling, we recruited English- and Spanish-speaking caregivers of CMC receiving home health nursing services to achieve relatively balanced participation by diversity in medical conditions, race, ethnicity, and rural versus urban residence. Caregivers were identified through the hospital's palliative care/complex care program, and were recruited and interviewed by the research associate. Spanish-speaking caregivers were recruited and interviewed by a bilingual social worker.

Primary caregivers of CMC who received home health nursing services were eligible. CMC was defined as a child aged <18 years with a health condition that lasted or was expected to last  $\geq 12$  months and who: 1) received ongoing care from  $\geq 5$  specialists or providers, 2) depended on  $\geq 2$  forms of technology, 3) had  $\geq 3$  hospitalizations, or 4) had  $\geq 30$  days of hospitalization in the 6 months before the interview. Twenty interviews (15 English and 5 Spanish) of 26 caregivers were conducted between October 2012 and August 2013 at locations and times of caregivers' choosing. A language-appropriate interview guide ([Online Appendix A](#)) elicited caregivers' perspectives on home health services. To capture emerging concepts, the interview guide was revised as interviews progressed.

### NURSE FOCUS GROUPS

Fliers advertising the focus groups were distributed to HHN in several counties. Licensed nurses were eligible if they were employed by a home health agency and had provided nursing care for CMC at home during the past year. Twenty-seven nurses representing 6 offices of 4 home health agencies in the region volunteered to participate. Four focus groups were conducted with 18 nurses between October 2013 and January 2014 in public settings in 2 counties at times convenient for the majority. Nine HHN volunteered but did not attend the focus groups. Focus groups were moderated by the research associate using a guide designed to elicit home health care experiences. The focus group guide ([Online Appendix B](#)) was developed using themes that emerged from caregiver data. Food was provided.

**Table 1.** Characteristics of 20 Children With Medical Complexity Whose Caregivers Participated in Interviews

Characteristic	Value
Age, y	8 (0.7–16)
Gender	
Male	12 (60%)
Female	8 (40%)
Race	
White	13 (65%)
Black	4 (20%)
Multi-racial	3 (15%)
Ethnicity	
Hispanic	5 (25%)
Non-Hispanic	15 (75%)
Residence	
Urban	12 (60%)
Not urban	8 (40%)
Health insurance	
Medicaid only	15 (75%)
Medicaid and private	5 (25%)
Medical complexity	
Child receives ongoing care from $\geq 5$ specialists/ services not generally needed by children	19 (95%)
Child depends on $\geq 2$ forms of technology for survival	19 (95%)
Child hospitalized $\geq 3$ times in the past 6 months	2 (10%)
Child spent $\geq 30$ days hospitalized in the past 6 months	2 (10%)
Diagnostic categories	
Genetic (chromosomal abnormalities, malformation, syndromes, birth defects)	9 (45%)
Perinatal events (prematurity and perinatal hypoxic ischemic encephalopathy)	5 (25%)
Neurological impairment from acquired causes (infection, injury)	6 (30%)
Technology dependence	
Gastrostomy/gastrojejunostomy	20 (100%)
Tracheostomy	15 (75%)
Chronic mechanical ventilation	9 (45%)
Duration of home health nursing services, y	5.9 (0.6–16)
No. of nursing hours/week child is receiving, h	80 (20–126)
Multiple nurses assigned to case	18 (90%)

Data are presented as mean (range) or n (%).

### DATA ANALYSIS

Interviews and focus groups were audiorecorded and transcribed verbatim. A codebook was developed deductively and was revised inductively as coding progressed. Both authors coded the transcripts independently using ATLAS.ti software,<sup>10</sup> and then compared their coding. Discrepancies in coding were discussed and resolved. Thematic analysis was conducted.<sup>11</sup> The content of each code was summarized by one author, and reviewed and validated by the other. By repeated review of the coded content through an iterative process, recurrent themes and sub-themes related to quality of home health care were identified by their prevalence and salience in the data. Both authors discussed the data until agreed themes were outlined and thematic saturation was reached.

## RESULTS

Characteristics of CMC whose caregivers were interviewed are presented in [Table 1](#). Twenty-six caregivers included 13 mothers, 1 grandmother, and 6 mother–father

Download English Version:

<https://daneshyari.com/en/article/5716853>

Download Persian Version:

<https://daneshyari.com/article/5716853>

[Daneshyari.com](https://daneshyari.com)