

Transitioning Children With Medical Complexity From Hospital to Home Health Care: Implications for Hospital-Based Clinicians

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ABSTRACT

OBJECTIVES: There is limited research about best practices for transitioning children with medical complexity (CMC) from hospital to home. Our objectives were to describe issues related to transitioning CMC from hospital to home health care and identify strategies to improve this transition.

METHODS: This qualitative study was conducted in western North Carolina between 2012 and 2014 and involved a focus group of 14 hospital- and community-based stakeholders and 4 focus groups of 18 home health nurses. Focus groups were audio-recorded and transcribed verbatim, and transcriptions were managed in ATLAS.ti software. By using content analysis, recurrent themes related to transitioning CMC from hospital to home were identified.

RESULTS: Themes in 4 domains emerged. (1) Home health orders: home health care providers desired hospital-based providers to write accurate and specific orders, notify them in advance about discharge to order specialized supplies, and avoid changing orders at the last minute. (2) Communication: participants found discharge summaries useful but did not always receive them. Communication between hospital-based clinicians, home health care providers, and the child's primary care physician about the hospitalization and home care was important. (3) Resources: home health care providers needed hospital-based clinicians to be a resource during the early period of transition home. (4) Caregiver preparation: participants emphasized caregiver preparation about medical care of CMC, home health nursing, and the differences between hospital and home care practices in the care of CMC.

CONCLUSIONS: There are gaps in the system of transitional care of CMC. Potential strategies to improve transitional care of CMC between the hospital and home health care services exist.

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Children with medical complexity (CMC) are a subgroup of children with functional limitations, technology dependence, and high need for health services.¹ CMC compose a disproportionate share of pediatric hospitalizations, hospital days, and readmissions.^{2,3} They receive care from many providers within a medical neighborhood, including primary and specialist physicians. Additionally, some CMC, especially those dependent on medical technology, require the services of home health nurses, durable medical equipment (DME) providers, and other community providers.^{1,4} Hence, transitioning CMC from hospital to their home environment is complicated by the need to coordinate care between hospital-based providers and multiple providers in the community.⁴ This fragmentation in care delivery puts CMC at an increased risk of medical errors, unsuccessful discharges, and recurrent readmissions and contributes to caregiver burden.^{3,5–9}

Improving transitional care is one strategy to reduce health care costs and rehospitalizations for CMC. National organizations have advocated for high-quality transitional care that involves seamless transitions of patients from acute inpatient care settings to the community.^{6,10} Transitional care practices vary widely within and across hospitals and regions and there is growing evidence that the current transitional care systems are inadequate to support the health of CMC and their families.^{11–15}

Despite the highlighted importance of transitional care by national organizations, research is limited on best practices for transitioning CMC from hospital to home health care. Moreover, studies on transitioning CMC from hospital to home are limited to the perspectives of parents,^{12,13} and primary care and hospitalist providers.¹⁵ The perspectives of home health care providers (home health nursing and DME providers) about transitional care have not been described. To address these gaps, we sought to describe issues related to transitioning CMC from hospital to home health care, especially including home health care

providers' perspectives, and identify strategies to improve this transition.

METHODS

This qualitative study had 2 parts: (1) a stakeholder focus group and (2) 4 home health nurse focus groups. The Institutional Review Board of Wake Forest School of Medicine approved the study.

1) Stakeholder focus group: In May 2012, in an effort to improve the transitional care of CMC from hospital to home health care providers, we convened a meeting of stakeholders representing multiple community agencies and departments in the tertiary care children's hospital. This was a special session of one of the regularly scheduled community coalition meetings and was held in a community agency. Fourteen hospital and community stakeholders from multiple agencies and hospital services participated in a focus group discussion at this meeting. The focus group was part of a quality improvement effort and not a research study. One of the authors (SG) facilitated the focus group using a guide developed specifically for this purpose (Supplemental Information). Participants were informed of the discussion being recorded, but written informed consent was not obtained. Our institution's institutional review board does not require obtaining signed consent for quality improvement initiatives. Food was provided. Monetary incentive was not provided. Participant-level information was not obtained. The duration of this focus group was 78 minutes.

2) Home health nurse focus groups: as part of a larger qualitative study on home health nursing services for CMC, 4 focus groups of 18 home health nurses were conducted between October 2013 and January 2014. Details of the nurse focus groups are published in a previous article from this study.¹⁶ Home health nurses were recruited through fliers distributed through home health agencies' managers. Nurses were eligible if they were licensed, employed by a home health agency, and had provided nursing care for CMC at home during the past year. Focus groups were conducted

in public settings in 2 counties at times convenient for the majority. Focus groups were moderated by one of the authors (SG) using a guide designed to elicit nurses' experiences related to home health nursing services for CMC (Supplemental Information). Participants signed informed consent, completed a brief survey before the focus group, and received food and \$25 incentives. The mean duration of the groups was 114 minutes (range: 80–165).

All focus groups were audio-recorded and transcribed verbatim for thematic content analysis.¹⁷ We used ATLAS.ti (Version 6.2; Humboldt, Germany), a software designed to organize and manage textual qualitative data.¹⁸ Using a collaborative, iterative process, authors reviewed transcripts and coded text using a topical coding guide to ensure consistency in analysis and to increase internal validity. Topical codes were supplemented with emergent codes as analysis proceeded. After coding, we abstracted segments of text by individual codes as well as groups of related codes using ATLAS.ti. Only themes related to transitioning CMC from hospital to home are presented in this article.

RESULTS

Stakeholder focus group participants included 9 hospital-based providers (2 attending physicians, 2 resident physicians, 2 nurse coordinators, and 3 social work coordinators) and 5 representatives of community agencies (1 from a home health nurse agency, 1 from a DME company, 1 from a hospice agency, and 2 from a community care coordination program). Characteristics of home health nurse focus group participants included a median age of 43 years (range: 27–66 years), and median duration of practice of 7 years (range: 2–18 years). A total of 13 were registered nurses and 5 were licensed practical nurses; 7 provided shift nursing, 3 provided skilled nursing visits, and 8 provided both shift and skilled nursing.

Six themes within 4 domains related to transitional care are presented below with illustrative quotes. Participants are

identified by letters and numbers in brackets after the quotes. FGS indicates stakeholder focus group; DME and HHA are representatives of DME company and home health agency, respectively. HHN participants are identified by focus group (FG) and nurse identification numbers. Potential strategies to improve transitional care were derived on the basis of the data and are described in Table 1.

Domain 1: Home Health Orders

Theme 1: Participants Wanted Home Health Orders To Be Specific and Accurate

Home health nurses had to abide by physician orders when delivering home care for CMC. Focus group participants agreed that home health orders should be accurate and specific so that home health agencies can develop the child's home health plan of care (Form-485). DME providers wanted specificity in orders about supplies (eg, gastrostomy tube size). Lack of accuracy and specificity in discharge orders

TABLE 1 Strategies Identified by Participants To Improve Transitional Care, by Domain

Strategies
Home health orders
Physicians writing accurate and specific orders for home care
Physicians writing orders for home supplies well in advance of discharge
Communication
Hospital sending discharge summaries to agencies
Clinicians communicating with home health providers about CMC's medical and social situations
Resources
Nurses providing child-specific clinical training ("orienting") to home health providers
Identifying hospital-based clinician(s) to serve as a resource(s) for home health providers
Physicians communicating with CMC's PCP
Caregiver preparation
Preparing caregivers about clinical care of CMC
Preparing caregivers about home health nursing services
Preparing caregivers about differences between hospital and home care

made it difficult for home health care providers to deliver care for CMC at home.

I can't give an over-the-counter. I can't give anything without an order. I can barely give the kid water without an order. (FG2, N05)

If they're coming from a hospital, not in this local area, and you don't get clear orders on equipment, you may not get what they need when they arrive in the home. (FGS, HHA)

When they write a new script, they could write a complete order instead of just a couple of scratches because we often... have to go back and get orders clarified to read properly so we can actually administer medication ordered to do the treatment because they'll leave a duration of antibiotics or things like that. (FG4, N18)

Theme 2: Participants Wanted Home Health Care Orders To Be Finalized Well Before Discharge

Late changes to orders at the end of hospitalizations were problematic for home health care providers and might indicate that children were not being discharged in a stable condition. Moreover, DME providers needed advance notification to order special equipment and supplies before the child's discharge. Changes made to the equipment and supply orders (eg, tracheostomy or gastrostomy tube size) just a few days before discharge were problematic for these participants. Such last-minute changes risked the child not receiving the appropriate backup equipment and supply at home.

A lot of times, what we'll run into is like a G-tube size. Maybe they went from a 12 French 1.2 to a 12 French 1.0... it's a big difference in making sure that you have a backup G-tube when you get home, because the one that's in could break the hour we get home. So, it's nice to have a little bit of a heads-up so that we can make sure you are not making a return trip just because of a small change like that. Or trach size is another thing that will frequently change 2 days before going home... (FGS, DME)

Domain 2: Communication

Theme 3: Discharge Summaries Were Useful Sources of Information for Home Health Providers

Participants voiced that home health care providers needed clinical information about CMC's hospitalizations. They said that they "always" needed discharge summaries to understand the child's clinical condition and obtain home health equipment and services. For example, documentation about desaturation in the hospital was needed for insurance to approve oxygen at home. Sometimes discharge summaries did not contain all the needed information to provide home care. Home health care providers, especially DME providers, did not always receive discharge summaries. When asked how this issue could be resolved, one nurse mentioned:

Make it standard practice that if they have home health, you send home a copy of the discharge summary... But there is no mechanism in place for us to be able to get that information without going through 12 steps and the 12 apostles and probably still not getting it (FG2, N08)

Theme 4: Communication With Hospital-Based Clinicians Was Desired by Home Health Care Providers

Participants desired communication, before discharge, between hospital-based clinicians and home health care providers about children's medical information. They said that nurse-to-nurse communication about a child's condition was needed. This communication helped home health nurses to gain understanding of the subtleties of CMC's condition. DME providers wanted information about the rationale for use of equipment, settings, and potential problems with equipment. Home health nurses mentioned that in addition to clinical information, they needed information about caregivers, family and other social issues. DME providers liked to know the time the child was expected at home so that they can be prepared to continue the child's care at home. However, this communication was often lacking.

...but I do need to know if there is 2 parents, 10 kids, no dogs, snakes, if CPS [child protective services] is involved...so we can paint a picture for the [home health] office that is going to prepare to bring that child home. (FGS, HHA)

Domain 3: Resources

Theme 5: Home Health Care Providers Needed Resources for Clinical Problem-Solving, But They Did Not Consistently Receive These Resources

Home health care providers in this study wanted hospital-based clinicians to serve as resources for them during the early posttransition period from hospital to home. Some suggested a nurse-to-nurse hand-off at the time of transition and being trained or "oriented" about child's care by hospital-based nurses as potential strategies to provide continuity of care.

...before they [children] come home, it would help if...you have a couple of primary care nurses that could go to the hospital and see what is going on with that child there, with the clinical manager. Because that way, there'd be continuity of care. It would be what they [hospital nurses] have been provided, and then you go home and you have a couple of nurses that have had that training. (FG3, N12)

The transition period was considered a difficult period because of the lack of clarity about the providers in charge of the child's care. Home health care providers often did not know whom to contact if there was a problem after discharge. Some mentioned having the contact number for the attending physician to call if they had a question. Some participants felt that primary care physicians (PCPs) were often not comfortable being a resource for home health care providers after children's discharge from the hospital, especially for problem-solving equipment problems. Many mentioned that communication of hospital-based clinicians with the child's PCP about the child's hospitalization and discharge plan would be helpful.

Well, is the PCP going to be available when we get home and we have a

question? Because we will always have a question. (FGS, DME)

Domain 4: Caregiver Preparation

Theme 6: Participants Considered Preparing Caregivers About Home Care, Home Health Nursing, and Home Care Practices To Be Important

Preparing caregivers for home care was desired by participants. They mentioned that caregivers had to learn quickly to provide medical care for their children at home. Caregivers also needed to be prepared about home health nursing, possible staffing difficulties, and the differences between hospital and home care. Participants felt that it was the responsibility of hospital-based clinicians to prepare caregivers, but there was variability in how caregivers were prepared.

I think they [caregivers] should be prepared as much as the nurse. Because there is always those scenarios where they are going to be left there. That's what I've seen...Maybe a nurse is sick and calls out and they can't get someone [to fill in for her in the home]. They need to know. (FG1, N02)

...[Hospital staff] don't ever prepare the family appropriately to handle a true emergency situation...Some of them are over-taught and some of them are briefed and then sent out the door. I think if the process was the same for all families, it would be great. (FG3, N11)

There were differences between hospital and home care practices in using supplies, primarily because insurance policies had limits on the supplies provided for home care. This necessitated cleaning and reusing equipment and supply at home, which were different from practices in the hospital. Home health care providers said that caregivers were often not prepared for these changes in practices between hospital and home.

Sometimes parents don't believe us when we tell them there is limits on things, because they have seen that 1-time use, chuck it, and in the trash. (FGS, HHA)

...even if there is a policy to throw that trash away, they [nurses] are explaining as they are throwing it away, "I'm going to throw this away, but at home you're going to clean this, and this is the process on how to clean it and why," and etc. That way that's already kind of explained before I come into the room and say, "Well, you are only going to get 2 every 10 weeks." (FGS, DME)

DISCUSSION

To the best of our knowledge, this is the first study with a focus on transitioning CMC from hospital to home health care. With our study findings, we provide further evidence for a multidisciplinary, standard approach to discharging CMC from the hospital to home environment.¹⁹⁻²² Potential strategies identified in this study can be incorporated by hospital-based clinicians to improve transitional care of CMC (Table 1).

Home health orders should be comprehensive and encompass respiratory, feeding, and general nursing care (ie, oral care, positioning); detail management of equipment and supplies; and specify clinical parameters and plan for management of clinical situations outside of these parameters. Home health orders should be sent to DME companies as well so that they can order the necessary equipment and supplies on time and ensure that the equipment and supplies are available when the child arrives at home. Hospital-based providers should be aware of policies related to home health equipment and supplies and ensure that home health care orders are consistent with these policies. Resident physicians should be educated on home health care needs of CMC, including how to write home health care orders. On the basis of our study results, we have created a template of home health care orders within the electronic medical record (available on request). Comprehensive care plans and standardized discharge process for CMC have been shown to decrease length of stay and readmission rates and improve caregiver satisfaction.¹⁹⁻²³ In future studies, researchers should evaluate the effect of implementing standardized home health orders on health care outcomes of CMC.

We found communication between hospital-based providers and home health care providers to be important. This communication should include clinical as well as nonclinical information. Discharge summaries should accurately summarize the hospitalization and ongoing medical needs of the child and be sent to home health care providers as soon as possible. Home health care providers need direct clinical support from hospital-based clinicians familiar with the care of their clients, especially in the first few days after transition from the hospital to home. However, they are often unable to obtain this clinical support from PCPs or hospitalist physicians. One potential strategy to provide clinical support for home health care providers is for hospital-based providers to consistently communicate with PCPs. Substantial research exists on the importance of and the gaps in hospitalist-PCP communication about hospitalized CMC.^{15,24} Communication of hospital-based providers with PCPs should include information about home health care needs in addition to the child's hospital course. Another strategy to improve transitional care is for hospital-based providers to be a resource for home health care providers in the early days to weeks after discharge from the hospital to ensure continuity of care. Home health care agencies are open to working more collaboratively with providers of other agencies.²⁵ One study reported a model in which hospital-based clinicians and home health nurses held joint case conferences.²⁶ Another report described a case study of a multidisciplinary approach to caring for CMC in which home health nurses were trained by hospital-based clinicians.²⁷ Care coordinators within complex care programs could also serve as a resource for home health care providers in the transition process.¹⁹ Such models of transitional care should be evaluated.

Home health care providers emphasized the importance of preparation of caregivers for home care. This is similar to caregivers' perspective on preparing them for home care of their children.^{12,13} Preparation should include education about clinical care of the child (including the ability to respond

to medical emergencies), navigating home health nursing services, and the differences in nursing practices between hospital and home. Adequately preparing caregivers by using a standardized educational process has been shown to improve the transition into the home environment and reduce caregiver burden.^{20,23} In a randomized controlled trial, Collier et al²⁸ showed postdischarge coaching to reduce readmissions. It remains to be seen whether caregiver preparation about home care can reduce readmissions of CMC.

There are certain limitations to our study. This study was focused on the transitional care experiences of CMC receiving home health nursing services. Hence, the findings cannot be generalized to the experiences of CMC who have home health care needs other than home nursing services. This study was limited to 1 community in western North Carolina. Home health care services vary greatly between hospitals and regions around the country. However, the gaps in transitional care we identified in our study are likely to be issues nationwide and the strategies we identified can be modified to fit the needs of other communities. The stakeholder focus group included hospital-based providers and was not entirely composed of home health care providers. The stakeholder focus group was focused on transitional care; however, the nurse focus groups were part of a larger study in which transitional care was only 1 component. Also, the stakeholder group was conducted 17 months before the nurse focus groups. Nevertheless, domains and themes were consistent between the stakeholder focus group and the nurse focus groups.

CONCLUSIONS

There are numerous gaps in the current system of transitioning CMC from the hospital to home health care providers. However, potential strategies to improve transitional care exist. Researchers of future studies should determine if implementation of the strategies identified in our study improve outcomes of CMC, including reduction in readmission after discharge from the hospital and adverse events and improved

satisfaction of caregivers and home health care providers.

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