

Home Health Care Availability and Discharge Delays in Children With Medical Complexity

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abstract

BACKGROUND: An increasing proportion of pediatric hospital days are attributed to technology-dependent children. The impact that a pediatric home care nursing (HCN) shortage has on increasing length of hospital stay and readmissions in this population is not well documented.

METHODS: We conducted a 12-month multisite prospective study of children with medical complexity discharging with home health. We studied the following 2 cohorts: new patients discharging for the first time to home nursing and existing patients discharging from the hospital to previously established home nursing. A modified delay tool was used to categorize causes, delayed discharge (DD) days, and unplanned 90-day readmissions.

RESULTS: DD occurred in 68.5% of 54 new patients and 9.2% of 131 existing patients. Lack of HCN was the most frequent cause of DD, increasing costs and directly accounting for an average length of stay increase of 53.9 days (range: 4–204) and 35.7 days (3–63) for new and existing patients, respectively. Of 1582 DDs, 1454 (91.9%) were directly attributed to lack of HCN availability. DD was associated with younger age and tracheostomy. Unplanned 90-day readmissions were due to medical setbacks (96.7% of cases) and occurred in 53.7% and 45.0% of new and existing patients, respectively.

CONCLUSIONS: DD and related costs are primarily associated with shortage of HCN and predominantly affect patients new to HCN. Medical setbacks are the most common causes of unplanned 90-day readmissions. Increasing the availability of home care nurses or postacute care facilities could reduce costly hospital length of stay.



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WHAT'S KNOWN ON THIS SUBJECT: Reports increasingly implicate a shortage of pediatric home care nurses with prolonged length of hospitalization for children with medical complexity. The magnitude of this problem as well as the contribution of home care failures to hospital readmission is largely unknown.

WHAT THIS STUDY ADDS: A home care nursing shortage is the primary cause of delayed hospital discharge for children discharging to home care, resulting in increased length of stay and costs. Medical setbacks, not failed home care, accounted for most nonelective 90-day readmissions.

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TABLE 1 Comparison of New and Existing Patients

	New Patients, <i>n</i> (%)	Existing Patients, <i>n</i> (%)	Difference, %	<i>P</i>
No. patients, <i>n</i>	54	131	—	—
Demographic characteristics				
Male	27 (50.0)	63 (48.1)	1.9	.816
Race				.341
White	37 (68.5)	97 (74.0)	−5.5	
African American	5 (9.3)	16 (12.2)	−3.0	
Other or unknown	12 (22.2)	18 (13.7)	8.5	
Age at discharge, <i>y</i>				<.001
<1	34 (63.0)	11 (8.4)	54.6	
1–4	15 (27.8)	56 (42.7)	−15.0	
≥5	5 (9.3)	64 (48.9)	−39.6	
English language	47 (87.0)	117 (89.3)	−2.3	.661
Interpreter needed	5 (9.3)	13 (9.9)	−0.7	.891
Patient residence in Twin Cities metropolitan counties	36 (66.7)	77 (58.8)	7.9	.322
Private insurance	27 (50.0)	53 (40.5)	9.5	.238
Clinical characteristics				
Chromosomal abnormality and/or syndrome	16 (29.6)	43 (32.8)	−3.2	.675
Primary diagnosis for inpatient admission				.006
Brain injury and/or central nervous system disorder	8 (14.8)	55 (42.0)	−27.2	
Lung or airway obstruction disorder	23 (42.6)	26 (19.8)	22.7	
Neuromuscular disorder	4 (7.4)	10 (7.6)	−0.2	
Cardiac	4 (7.4)	7 (5.3)	2.1	
Gastrointestinal	3 (5.6)	8 (6.1)	−0.6	
Other	12 (22.2)	25 (19.1)	3.1	
Discharge characteristics				
Discharged to home with family	52 (96.3)	123 (93.9)	2.4	.516
Patients with DD	37 (68.5)	12 (9.2)	59.4	<.001
Causes of DD				.019
Patients waiting for home care nurses	25 (46.3)	3 (2.3)	44.0	
Patient or family	4 (7.4)	3 (2.3)	5.1	
Social situation	2 (3.7)	4 (3.1)	0.7	
Other	6 (11.1)	2 (1.5)	9.6	
Average hospital LOS, d	124.9	11.5	113.4	<.001
LOS before DD, d	98.4	10.3	88.0	<.001
LOS after medically ready for discharge, d	26.5	1.1	25.4	<.001
DD d, total of all patients	1432	150	—	—
Due to waiting for home care nurses	1347 (94.1)	107 (71.3)	22.7	<.001
90-d same-hospital readmission rate	29 (53.7)	59 (45.0)	8.7	.288

—, not applicable.

Children with medical complexity (CMC) account for one-third of all pediatric health care costs, and 80% of that is spent on hospitalization.¹ Decreasing health care use by CMC must address inefficiencies in the use of inpatient and ICU resources.² The impact a shortage of home care nursing (HCN) has on hospital length of stay (LOS) for this population in a region without

postacute or long-term care facilities is inadequately studied.

Technology-dependent CMC often require extended hours of HCN to facilitate a safe transition to home, minimize family burnout, and reduce the risk of readmissions. The demand for HCN has increased in recent decades^{3–7} with the largest increases for children <5 years of age.⁸ The increase is due in part to technological innovations that have

augmented survival of CMC and pressures to shift care from hospital to community settings.^{3,9–11}

Although nonclinical factors such as discharge planning, home care funding and availability, and family training^{9,12–21} may delay discharge of CMC, most delayed discharge (DD) studies have been focused on children requiring mechanical ventilation.^{9,12–14} Using a modified version of a Delay Tool,^{22–24} this study prospectively documents causes, frequency, days, and costs associated with DD in CMC deemed medically ready for discharge with HCN. Causes and frequency of readmissions are also documented to study the role home care failures have on rehospitalization.

METHODS

Study Design and Participants

This was a 12-month prospective study that involved CMC discharged with HCN. The study occurred from April 1, 2016, through March 31, 2017, from 4 children’s hospitals in Minnesota (Children’s Minnesota, University of Minnesota Masonic Children’s Hospital, Mayo Clinic, and Gillette Children’s Specialty Healthcare). Care coordinators identified CMC after admission that met inclusion criteria (Supplemental Table 3) for study personnel. However, inconsistencies exist in defining CMC²⁵; for this study, the defining factor for inclusion was the need for ≥8 hours per week of HCN at hospital discharge. Eligible patients were stratified as new or existing. A new patient was defined as a newborn or child not deemed medically complex before hospitalization who met inclusion criteria at discharge requiring HCN. An existing patient was previously defined as medically complex with established HCN before admission and continued to meet inclusion criteria at discharge to HCN. Care coordinators actively involved in

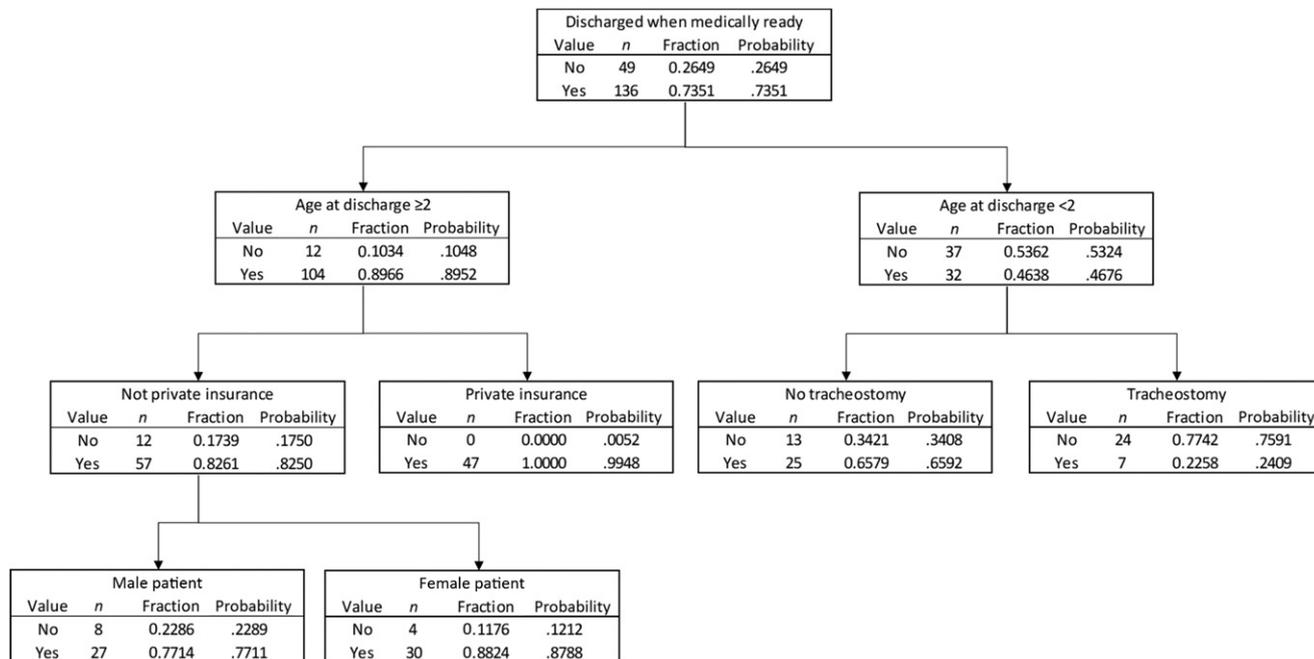


FIGURE 1 Partitioning or discriminating factors for determining discharged when medically ready. For the outcome “discharged when medically ready,” 4 variables were found to partition the study population. The approximate R^2 for these 4 factors was 32.3%. Age at discharge, with a split at 2 years of age, was the most important factor. Thirty-seven children <2 years of age (54%) experienced a DD; 31 of these children had a tracheostomy. Among these 31 children, 24 (77%) more frequently experienced a DD. Among children 2 years of age and older, only 12 (10%) experienced a DD. All 12 had nonprivate insurance with more male patients experiencing DD than female patients.

patient care communicated with attending physicians and study personnel regarding the time line for when a patient was deemed medically ready for discharge. Patients were excluded if discharge occurred after the 12-month study period, if parents or guardians declined chart review for any research purposes, or if death occurred before discharge. This study was approved by each hospital’s institutional review board with a waiver of consent.

Data Collection

Data were collected on worksheets (Supplemental Information) and entered by study site personnel after discharge into a secure encrypted Web site. Designated individuals at each participating study site were issued user identifications and access passwords. Patient identification numbers assigned to eligible patient cases were specific to the study site and designated individuals. Data

were deidentified before entry, and only the designated individuals could link data records to patient medical records. For patients who remained hospitalized after being deemed medically ready for discharge, a modified delay tool (Supplemental Information) was used to identify causes and number of delayed days. The number of DD days attributed to the availability of HCN to staff a patient at home was specifically assessed. Causes of unplanned same-hospital readmissions within 7 and 90 days postdischarge from the index hospitalization were assessed by study site personnel through hospital medical records. Readmissions were not used as index hospitalizations. Unplanned readmissions were categorized as medical setback, home care failure with nursing staff, medical equipment failure, or inability of the family to care for the child at home.

Cost Analysis

We estimated the resource implications of DD due to availability of HCN as the difference between avoidable hospital cost and the cost of HCN had patients been discharged to HCN when they were medically ready for discharge. For each DD day, we estimated hospital cost on the basis of recent studies of CMC.^{26–29} Inflating estimates from these studies to 2017 dollars using the Consumer Price Index for hospital and related services, we estimated the cost per hospital day for CMC at \$3932. The cost of HCN is based on Medicaid reimbursement rates for home care in Minnesota. We estimated HCN cost at \$40.72 per hour, given the mix of registered nurse and licensed practical nurse hours.

Statistical Analysis

Data were entered, downloaded, and converted to SAS version 9.4 (SAS Institute, Inc, Cary, NC) for analysis. Patients were identified as new or

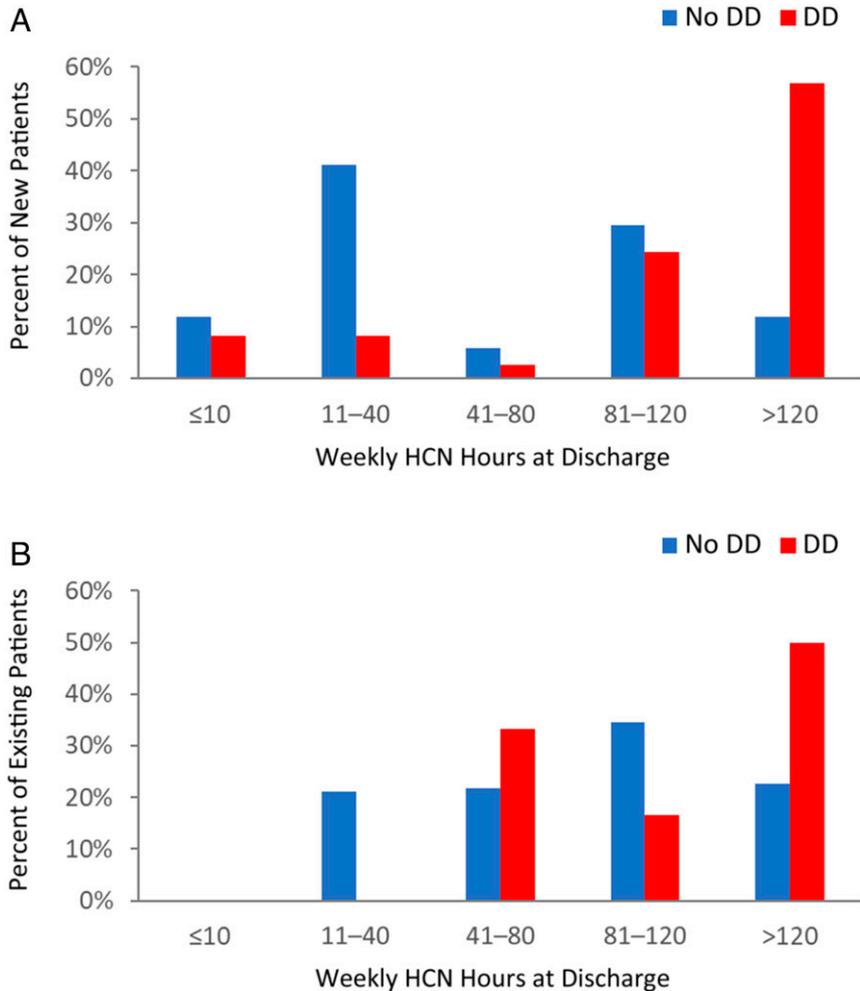


FIGURE 2 Weekly HCN hours at discharge for patients with and without DD. A, New patients. B, Existing patients.

existing regarding HCN. Differences between these 2 patient groups were assessed by using χ^2 for categorical variables (race, age group, primary diagnosis, and causes of DD) or Student's *t* test for continuous or binary variables (average hospital LOS, total discharge days, discharge days attributable to lack of home care nurse availability). An additional analysis examining the association between the allocation of HCN hours and patient care needs (invasive ventilation and tracheostomy) was conducted by using χ^2 analysis. Statistical significance was set as $P < .05$ for all tests.

An exploratory data approach using classification and regression tree (CART) analysis was used to

examine the association between 2 defined outcomes of interest (discharged when medically ready and 90-day readmissions) and hospitalization episode attributes (patient demographic variables, LOS, and medical treatments). CARTs are machine-learning methods for constructing prediction models from data that will detect potential interactions of significance.³⁰ The models are obtained by recursively partitioning the data space and fitting a simple prediction model within each partition to allow for the identification of variables that are most efficient in classifying levels of the outcome under investigation.

RESULTS

Study patients consisted of 54 new and 131 existing patients. New patients were younger than existing patients. There was no statistical difference between these groups by sex, race, primary language, need for an interpreter, location of residence, and private insurance (Table 1). Clinically, new and existing patients had similar rates of chromosomal abnormality or syndrome but differed by the primary diagnosis. Specifically, new patients most likely had a primary diagnosis of lung or airway obstruction disorder, whereas brain injury or central nervous system disorder was the most likely diagnosis for existing patients (Table 1). The CART analysis (Fig 1) revealed that age, insurance, tracheostomy, and sex, but not rural residence or prescribed HCN hours, were the discriminating factors for determining if patients were discharged when medically ready. Discharge delay for new patients was more likely due to waiting for home care nurses than for existing patients. For existing patients, patient or family and social situations were as likely causes of DD as waiting for home care nurses (Table 1). Average days for all discharge delays was significantly different between new (26.5 days) and existing (1.1 days) patients. Waiting for home care nurses accounted for 94.1% and 71.3% of total DD days for new and existing patients, respectively. Among study patients, 175 were discharged from the hospital with their families, 9 to medical foster care, and 1 to an alternate hospital.

Nursing Hours

Figure 2 shows the distribution of HCN hours. The allotment of nursing hours was not significantly different between the 2 groups, and 72.2% and 80.9% of new and existing patients, respectively, received >40 hours per week. Extended hours of nursing care >120 hours per week

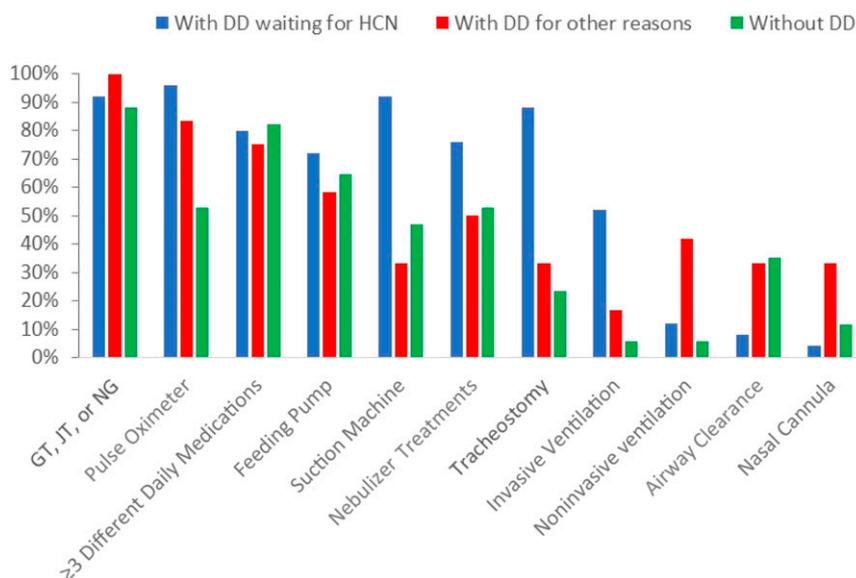


FIGURE 3 Medical equipment and/or therapies for new patients with and without DD and reason for DD. Of the 54 new patients, 25 had DD waiting for HCN, 12 had DD for reasons other than waiting for HCN, and 17 did not have DD. GT, gastrostomy tube; JT, jejunostomy tube; NG, nasogastric tube.

TABLE 2 Cost of DD Due to Waiting for HCN

	New Patients	Existing Patients	All patients
Patients with DD due to waiting for home care nurses	25	3	28
Total DD d waiting for home care nurses	1347	107	1454
Hospital costs for DD waiting for home care nurses	\$5 296 404	\$420 724	\$5 717 128
Average home care nurse h per d	15.7	15.5	15.7
Home care costs for DD d	\$713 398	\$55 927	\$769 326
Hospital cost less home care cost	\$4 583 006	\$364 797	\$4 947 802
Percent	86.5%	86.7%	86.5%
Averages per patient with DD waiting for home care nurses			
DD d	53.9	35.7	51.9
Hospital costs for DD waiting for home care nurses	\$211 856	\$140 241	\$204 183
Home care costs for DD d	\$34 511	\$22 546	\$33 229
Hospital costs less home care cost	\$177 345	\$117 695	\$170 954

Hospital costs per day were estimated at \$3932. The reimbursement or cost for HCN was estimated at \$40.72 per hour.

were prescribed for 100% (16 of 16) of new patients with invasive ventilation compared with 55.5% (15 of 27) of existing patients. The allocation of HCN hours was associated with invasive ventilation and/or tracheostomy ($P < .001$).

Medical Equipment and/or Therapies

Medical devices and therapies prescribed at discharge are shown in Fig 3. DD in new patients was associated with the presence of a tracheostomy tube (Fig 1).

Cost

There were 1454 DD days across 28 patients with DD who waited for HCN. This was an average of 51.9 days per patient. We estimated that the hospital cost for DD days across patients who waited for HCN was \$5.72 million for all patients, with most of that attributable to new patients (Table 2). The hospital costs would have been avoided had these patients' discharges not been delayed if HCN was available when they were medically ready. In contrast, they would have incurred HCN costs

estimated at \$769 326 over the comparable time period. Hence, the net costs avoided would have been \$4.95 million across 28 patients or \$170 954 per patient with DD.

Readmission Data

Unplanned readmissions were similar between new and existing patients. New patients, 29 of 54 (53.7%), had a total of 48 readmissions within 90 days, and 19% of those readmissions occurred within 7 days of discharge. Existing patients, 59 of 131 (45%), had a total of 102 readmissions within 90 days, and 12.7% occurred within 7 days of discharge. Collectively between both groups, 47.7% of readmitted patients had >1 readmission within 90 days. Medical setbacks were the cause for 96.7% of readmissions. The remaining readmissions were due to medical equipment failures ($n = 3$), home care failure ($n = 1$), and inability of the family to care for the child ($n = 1$). CART analysis of factors determining unplanned readmissions (Fig 4) identified a higher proportion of readmissions occurred in patients residing outside the Twin Cities metropolitan area (61%) versus patients residing in the metropolitan area (39%).

DISCUSSION

Approximately 5% to 7% of pediatric hospital discharges include home health care, and these patients are more likely to have multiple chronic conditions and technology assistance.^{31,32} Our prospective study involved only CMC being discharged with home health care to quantify the impact a home health nursing shortage^{25,33,34} may have on impeding discharge. We found that unavailability of HCN was the primary cause for 57.1% of discharge delays, accounted for 91.9% of DD days, and contributed to lengthier delays. Other studies involving children with home mechanical

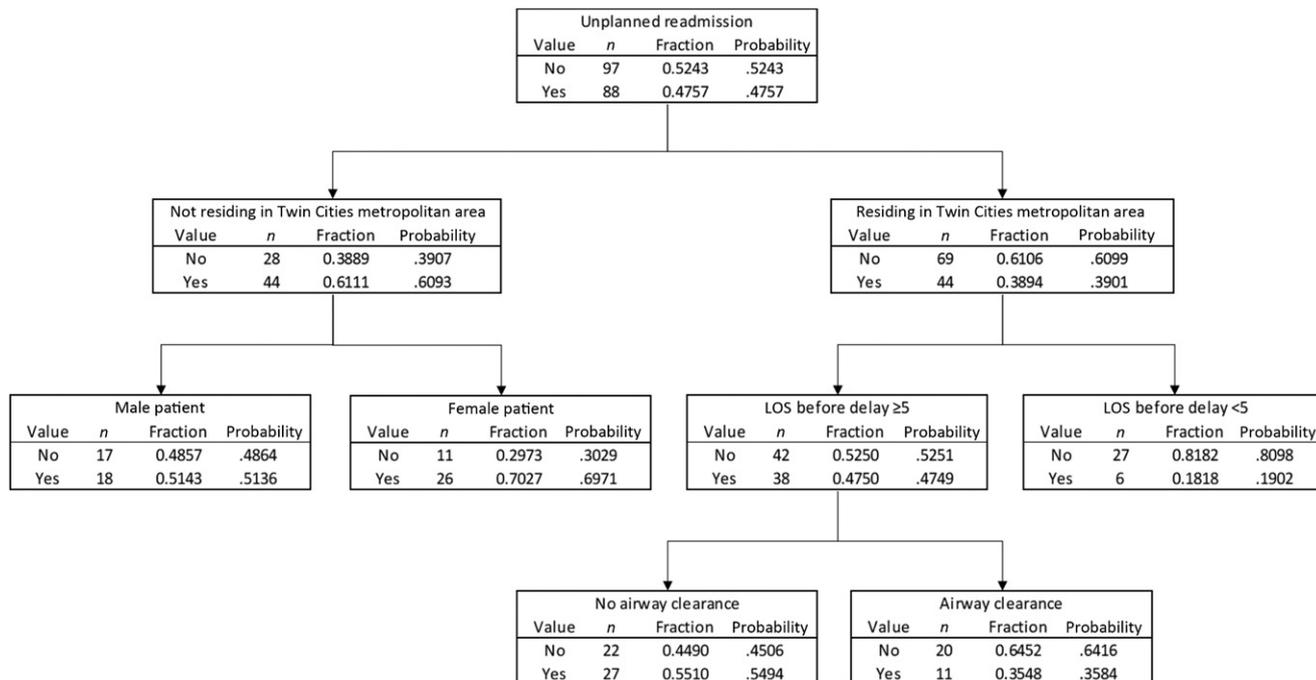


FIGURE 4

Partitioning or discriminating factors for determining unplanned readmission within 90 days. For the outcome “unplanned readmission within 90 days,” 4 factors were found to partition the study population. The approximate R^2 for these 4 factors was 9.2%. The location of residence was the most important factor. There were 88 children with an unplanned readmission within 90 days, with 72 residing outside the Twin Cities metropolitan area. Among these children, 44 (61%) experienced an unplanned readmission, with a greater proportion of unplanned readmissions among female patients than male patients. Among the 113 children residing in the Twin Cities metropolitan area, 44 (39%) had an unplanned readmission. For these children, an LOS of 5 days or longer with no airway clearance technology had a higher probability of an unplanned readmission.

ventilation had wide-ranging delay estimates from 19 days to 9.6 months.^{3,12–14} What our study adds is an estimate of the average length of DD and the average length of delay specifically attributable to the lack of HCN among pediatric patients discharged to HCN in a region without postacute or long-term care facilities.

The Minnesota Olmstead Plan requires that individuals with disabilities receive care and services in the most integrated setting. Currently, Minnesota has no postacute or long-term care facilities for CMC, and the focus is on discharge to home or community-based alternatives. Pediatric long-term care facilities extend medical care or services for CMC who can no longer be cared for in the home. Conceivably, availability of these alternatives might shorten acute care hospitalization. Authors of 1 report³⁵ identified that 25% of DDs were

due to the lack of HCN in a region without a postacute care facility. Children with tracheostomy spend fewer days in acute care hospitals when postacute care facilities are used.^{31,36} The lack of postacute care facilities³⁷ or transition centers to provide services for children still needing time to stabilize contributes to prolonged hospitalization in acute care hospitals.

Although DD, specifically attributable to the lack of HCN, occurred with new and existing home care patients, we found most delays were associated with patients new to HCN. Differences are likely attributable to established HCN for existing patients that reduces the likelihood and length of delays as well as parental familiarity caring for their child when HCN is unavailable. Having established HCN minimized associated discharge delays. In a previous report¹⁴ that identified home care funding and

medical foster care placement as the greatest barriers to discharge for ventilator-assisted children, the time from medical stability to discharge accounted for 73% ± 29% of the entire LOS. In our study, the number of days from medical stability to discharge averaged 21.2% of LOS for new patients with DD who waited for HCN. This prompted other institutions to implement discharge planning pathways for children as soon as they are identified as becoming technology dependent.^{15,19,38}

Discharge delays due to pediatric HCN shortage have worsened since 2001, when a Minnesota report³³ found a lack of HCN, or pending insurance approval, accounted for 205 delay days among 29 CMC. The demand for pediatric home care has increased in recent decades and will continue as medical advances for severely ill children increase life expectancy but without restoration of

full function.³⁻⁸ As this population of CMC grows, there is a proportionate increase in the degree of intensive medical technology use,² and this may impart a trade-off in mortality for morbidity.^{9,34} As an example, bronchopulmonary dysplasia has recently been associated with a 3% chance for survivors to be discharged from the hospital on mechanical ventilation,³⁹ commonly with HCN.

A unique outcome metric available for comparison from our study was the allotment of HCN hours. Authors of a 1991 report⁴⁰ from Minnesota identified that 64.5% of families received >9 hours per day, and 16% received 24 hours per day. HCN varied between 8 and 24 hours per day from other studies of tracheostomized children.^{14,34} In our study, >70% of patients received >40 hours of nursing per week, and as expected, new patients were more likely to receive more extended hours of care (>120 hours per week) than existing patients.

As the population of CMC continues to grow, there is a concomitant need for home care nurses. A reported shortage of pediatric HCN⁴¹ is multifactorial. New graduate nurses often perceive home care as a stepping stone for experience needed to gain hospital employment with better benefits and an hourly wage increase of \$10.³³ Authors of a recent study of pediatric chronic respiratory failure cases, which are likely cases for discharge to home care, found that increased LOS correlated with economic conditions when unemployment was low.²⁶ Although many home care nurses find their jobs rewarding, several factors impact retaining nurses beyond monetary factors.⁴² The job is socially isolating, not all families are welcoming, and as the level of acuity increases for CMC so does the intensity of nursing care needs. Prolonged and unplanned rehospitalizations of a home care

nurse's assigned patient(s) may contribute to extended periods of unemployment and subsequent migration to other opportunities for employment. This latter concept contributed to DD of patients who had preestablished nursing in our study.

From a value perspective, DDs have substantial financial implications, which we have estimated at \$170 954 per patient for this study. In some respects, this estimated an upper bound on avoidable costs because increasing the availability of HCN would require an increase in the home care reimbursement rate, which would increase the cost of home care for all patients. However, children discharged to HCN may experience less hospitalization than comparable children discharged without HCN.⁴³ Rehospitalization would increase costs avoided by the use of postdischarge HCN. DD has negative effects beyond increased costs for CMC. Prolonged hospitalization may affect child development contributing to health care disparities⁴⁴ and increase risk for iatrogenic errors.⁴⁵

Prolonged hospitalization in an acute care facility beyond what is necessary for the diagnosis and treatment of the acute medical problem leads to challenges in facility planning, bed use, and other resources. Technology-dependent children with recurrent or chronic medical problems are typically admitted to ICUs for stabilization and management because other areas of the hospital are not equipped to care for patients requiring ventilation. In many children's hospitals, patients who are ventilator dependent remain in NICUs or PICUs until discharge, occupying a scarce community resource and precluding the admission of other acutely ill patients. As reimbursement moves to a diagnosis-related-group system for payment, additional costs of caring for children in an ICU who do not

require ICU-level care will become a greater drain on institutional resources. Postacute care or transition facilities may extend care outside of acute care hospitals before unification with family at home and may be an acceptable solution for some families. A strong partnership between acute, postacute, and long-term care pediatric health care organizations must be a priority to provide the best care in the most appropriate physical and psychological setting for children.

With our study, we found 90-day readmission rates of 53.7% and 45% for new and existing patients, respectively. There are no other studies with readmission rates specifically for CMC discharged with extended hours of HCN. The high readmission rates in our study likely reflect the inherent medical fragility of a population discharged with extended hours of nursing care. Without the option for discharge to a postacute care facility, our population was discharged only after acquiring HCN. Conceivably, children who are technology dependent discharged to a postacute care facility may have a greater degree of medical supervision and stability before being discharged from the hospital than children discharged directly from an acute care hospital to HCN. Many of these readmissions may have been potentially preventable in our population.

Limitations of the study included an underestimation of the problem because some regional hospital systems involved in discharging comparable CMC patients were not included in the study. In addition, patients were excluded if they remained hospitalized at the end of the study or if parents or guardians declined chart review for any research purposes. The study included only same-hospital readmissions, but because these are CMC who are best served in tertiary children's hospitals, this

underestimation may be small. Families of existing patients may have been willing to discharge 1 or 2 days earlier and provide care before scheduled nursing shifts could be staffed. Costs not fully captured in our estimate of hospital costs include physician and ancillary charges, which if included, would have increased our estimate of avoidable costs. Lastly, this study was undertaken in a region without the option of postacute or long-term care facilities.

CONCLUSIONS

In a setting without postacute or long-term care pediatric facilities, lack of HCN accounted for the greatest obstacle to discharging a population of CMC with prescribed

HCN. The inability to staff medically stable CMC at home prolonged hospitalization and increased health care expenditures to a greater degree in new patients discharging for the first time to HCN than patients with preexisting home care. DD was associated with tracheostomy and younger age but not the number of prescribed HCN hours or rural residence. Expanding the availability of home care resources or postacute care facilities for this population could impact LOS. Unplanned 90-day readmissions were due to medical setbacks, not home care failures. The high prevalence of unplanned 90-day readmissions in our populations may have been potentially preventable but likely reflects the underlying fragility of

patients discharging with extended hours of nursing care.

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ABBREVIATIONS

CART: classification and regression tree
CMC: children with medical complexity
DD: delayed discharge
HCN: home care nursing
LOS: length of stay

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Supplemental Information

This supplement contains 3 parts that were used as study tools.

- Part 1: DD study worksheet for research personnel only; patient identifiers were not entered into the encrypted Web site;
- Part 2: modified discharge delay tool (examples of causes); and
- Part 3: modified discharge delay tool (definitions).

SUPPLEMENTAL TABLE 3 Inclusion Criteria

Inclusion Criteria
<21 y of age at time of discharge
Medically complex (all 3)
Multiple medications and/or therapies; 3 or more therapeutic interventions (medications, nutritional support, respiratory therapy, dialysis, airway clearance, oxygen, etc)
≥2 subspecialists involved
≥2 chronic medical diagnoses expected to last at least 12 mo or more
Technology dependent (1 or more of the following)
IV therapy medications (TPN, milrinone drips, etc, through central or PICC line)
Tracheostomy
Mechanical ventilation ≥8 h per d includes CPAP, BiPAP (invasive or noninvasive)
Oxygen therapy
Gastrostomy or jejunostomy
Airway clearance (includes vest, IPV, cough assist)
Extended h of HCN care ≥8 h per wk at discharge

PICC, peripherally inserted central catheter