

BRIEF REPORT

Identification of Fail Points for Discharging Pediatric Patients With New Tracheostomy and Ventilator

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BACKGROUND AND OBJECTIVES: The core mission of the Pulmonary Habilitation Program is to train and prepare caregivers for the care of a ventilated child in the home. It exists within a free-standing children's hospital. The program is supported by a multidisciplinary staff and serves ~100 children. Through standardizing electronic documentation with process-specific tracking for the discharge process, the Pulmonary Habilitation Program team sought to identify intervention opportunities for more efficient and effective discharges.

METHODS: The process of discharge was described using an iterative process, with the multidisciplinary team and discharge milestones noted in the medical chart.

RESULTS: Several nonmedical factors contribute to prolonged hospital stays, including parent training, approval from the state agency for home care, and staffing of home nursing. Children had median lengths of stay of 141 days (interquartile range, 68 to 177).

CONCLUSIONS: As a result of this initial investigation, application to the state agency and training for caregivers have been initiated sooner, when a tracheostomy is first placed.

ABSTRACT

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Drs Sobotka and Goodman conceptualized the study; Dr Sobotka conducted the statistical analyses and drafted the initial manuscript; Ms Hird-McCorry coordinated caregiver training and discharge planning for patients who were chronically ventilated, contributed data for the study, and gave clinical context and expertise; Dr Goodman collaborated for interpretation of results and critically reviewed the manuscript; and all authors approved the final manuscript as submitted.

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Children who require long-term mechanical ventilation represent a significant and increasing population of pediatric inpatients and account for \$1.5 billion in inpatient hospital expenditures annually.¹ The incident hospital stay, when the child first receives a ventilator, is particularly lengthy because care must be coordinated between members of the inpatient and outpatient interdisciplinary teams in addition to community funding sources before the child can be safely discharged home. Discharge planning algorithms previously described include participation by the family, medical team, case managers, social workers, and community representatives.²

Retrospective chart reviews have identified many nonmedical obstacles contributing to lengthy and costly incident hospital stays: approval of public funding, assignment of home nursing, need for housing alterations, and significant family psychosocial barriers.³⁻⁶ Although nonmedical obstacles have been identified, the extent of delay caused and evidence-based mechanisms to support efficient discharges have not been described.

Efficient, yet comprehensive, discharge of pediatric patients with technology dependence is a crucial component of quality improvement, particularly in the context of health finance reform and patient-centered outcomes.⁷ In this preliminary descriptive study, we seek to design a process-specific tracking document in the electronic medical record (EMR) to describe the current timeline and factors influencing the duration of tertiary care hospital stay for pediatric patients transitioning home for the first time with a ventilator, and we explore future opportunities for more efficient and effective discharges.

METHODS

Pediatric inpatients at Ann & Robert H. Lurie Children's Hospital of Chicago admitted and discharged from October 2013 to January 2015 were eligible for inclusion. The Pulmonary Habilitation Program (PHP) manages patients preparing for invasive home ventilation via tracheostomy. It is an interdisciplinary team led by a pediatric critical care physician within the PICU.

Participants were excluded from this analysis if they were previously living at home with the same technology and did not require any additional parent training or nursing hours.

Members of the PHP team gathered to develop a cause-and-effect (fishbone) diagram through an iterative process. This tool has been described for conducting root cause analysis⁸ and has been used previously in pediatric quality improvement research.⁹

Demographic and medical data were gathered on each subject and logged in the EMR flow sheet.

Illinois-Specific Details

In the state of Illinois, the Division of Specialized Care for Children (DSCC) is a state-funded agency that provides care coordination and administers resources for home nursing and durable medical equipment (DME) for medically complex children. It works directly with families to obtain state funding for home nursing and home modifications to prepare for the care of a child with complex needs. Participation in the DSCC home care program requires complex coordination between hospital case management and DSCC care coordinators.

Families may become eligible through either Medicaid or the Medicaid Home and Community-Based Services Care Waiver Program, augmenting private insurance to provide necessary home nursing services. Medical records and a detailed letter of medical necessity are sent to the DSCC case coordinator, who then completes an assessment of the home to ensure the patient's medical needs can be safely met. Parents interview nursing agencies and DME companies and make selections; the case coordinator prepares an in-depth packet and sends it to the Illinois Department of Health and Family Services. The contracted company independently evaluates the medical needs of the patient. Health and Family Services reviews, approves, and provides a monthly budget for home nursing services. The DSCC case coordinator, home nursing agency, and caregivers meet to allocate these financial

resources. Usually, patients requiring 24-hour ventilation support receive 16 to 18 hours/day of home nursing. Ideally the DME company also delivers equipment to the patient's hospital room before discharge to facilitate caregiver training on home equipment.

A major barrier to discharge has been staffing of home nursing. Home health nurses, a mixture of registered nurses and licensed practical nurses, are generally trained to care for patient with tracheostomies, ventilators, and other medical needs. DSCC requires that they have a minimum of 1 year of postgraduate nursing experience.

On occasion, delays in discharge can be minimized by using 3 transitional care facilities in Illinois with a total of 48 pediatric beds equipped to care for technology-dependent pediatric patients. Patients are discharged from inpatient units to these facilities as needed to continue caregiver training and discharge planning at a lower level of medical care; at times, however, the lack of available beds in these facilities means that children remain hospitalized in an ICU even if medically ready for discharge.

The Program

PHP was started in 1976 at Children's Memorial Hospital (now Lurie Children's Hospital) in Chicago, Illinois. The program aims to prepare parents to care for their ventilated child in the least restrictive environment, most often the family's home. The program currently serves ~100 children, and the team includes a medical director, pediatric physician staff, pediatric advanced practice nurses, a nurse coordinator, a social worker, a child life specialist, case management, and respiratory therapists with special expertise in family education.

Preparation for Discharge

The cause-and-effect (fishbone) diagram was generated through an iterative process by the PHP team (Fig 1). This diagram details potential fail points leading to a delay of discharge, and therefore potential opportunities for quality improvement. The steps for discharge were conceptualized

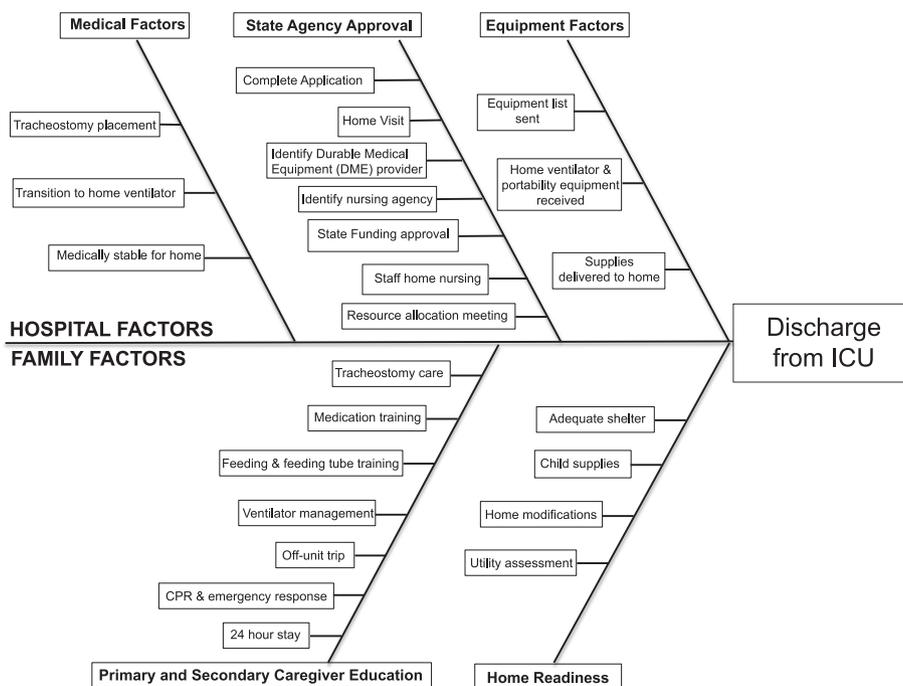


FIGURE 1 Fishbone diagram of factors delaying discharge from the ICU.

into 5 major categories: medical factors, state agency approval, equipment factors, primary and secondary caregiver education, and home readiness.

The process for discharging a patient requires medical stability, securing of home private duty nursing and DME, and training of caregivers. Medical stability includes stable respiratory status (≤ 0.4 fraction of inspired oxygen while on a portable ventilator and no escalation in ventilator parameters for ≥ 1 week) and minimal weekly changes in medical interventions to maintain clinical and hemodynamic stability.

Our program requires that a primary and secondary caregiver complete education and training, which may include tracheostomy care, feeding tube management, medication and feeding administration, ventilator management, cardiopulmonary resuscitation and emergency interventions, and portability training (using the child's stroller/wheelchair and portable equipment). Before discharge, caregivers are required to demonstrate their mastery of skills by caring for their child for 24 consecutive hours independently.

Once it is anticipated that discharge can occur within a week, the PHP team convenes a meeting including the caregivers, nurse practitioner, case manager, nurse coordinator, social worker, respiratory therapist, DSCC case coordinator, representatives from the home nursing and DME agencies, and a representative from a transitional care facility, if indicated.

Implementation of a Quality Improvement Documentation System

A flow sheet in the EMR was developed by the PHP team to track the steps to discharge: application dates to DSCC, completion of caregiver training, selection of home nursing agency, etc. In this study, we looked at time to each discharge component in an effort to improve our systems of care.

Evaluation of the Program's Impact and Study Design

Tracheostomy placement was considered time 0 in our analysis. Two subjects had tracheostomies at another hospital before transfer but were never home ventilated; time 0 was considered the day of admission to our hospital. Because of the small sample sizes, intervals between time 0 and

completed discharge task are presented as median and interquartile range (25th percentile, 75th percentile). All data are presented using descriptive statistics. Statistical analyses were completed with Stata 12.0 (Stata Corp., College Station, TX).

Institutional Review Board Approval

Lurie Children's Hospital institutional review board approved the study and considered it exempt; it included only retrospective medical record review.

RESULTS

Twenty-three children were eligible for study inclusion; 52% were male, mean age was 2.0 years (SD 3.9, range 0.3 to 17.7) at discharge, and the majority were < 1 year old ($n = 16$; 70%). The most common diagnosis was chronic lung disease due to prematurity ($n = 9$). Examples of other diagnoses included hypoxic ischemic encephalopathy, hypotonia, and chromosomal abnormalities. The median (interquartile range) length of stay (LOS) for the entire hospitalization, including time preceding tracheostomy placement, was 141 (68, 177) days, longer if the child was discharged home from the hospital versus a transitional care facility or was premature

(Table 1). The LOS after tracheostomy placement was 105 (56, 127) days. Contributing factors to LOS included medical stability for portable ventilator placement (13 [9, 50] days); approval of DSCC waiver (114.5 [84.5, 151] days); and completion of caregiver independence training (97.5 [74, 137] days). The average time for steps of discharge are displayed in timeline format (Fig 2).

Charts were reviewed to determine the reasons for delayed discharge. Eleven children were discharged, as planned, within a week of the meeting, and 12 children had delays. Six children remained hospitalized because of delays in home nurse staffing, which took at least an estimated 3 additional inpatient weeks per patient. Two children were delayed because of psychosocial reasons, 1 child was delayed because of family training, and 3 children had multiple factors affecting their delay.

Two participants were able to be discharged before DSCC approval because they had private insurance that provided interim home nursing. It is important to recognize that for these patients, LOS may have been longer if they had not had private insurance.

DISCUSSION

Children with technology dependence are expected to have long hospital stays because of complex medical care and overall health vulnerability. However, by standardizing the electronic documentation of the discharge process and examining data from our initial cohort, we identified that primarily nonmedical factors delay discharge. We hypothesize that earlier DSCC application and initiation of family training may decrease time to discharge, and since this analysis, both have been initiated sooner in our program.

Another major factor delaying discharge has been nurse staffing to support a child

with ventilator dependence at home. There is a paucity of nurses comfortable with both ventilator care and pediatrics. Also, children living in areas with fewer nurses (semirural) or where nurses may be less willing to go (some inner city neighborhoods) may have longer staffing delays.

Our data suggest that state agencies, outpatient nursing agencies, and inpatient care teams must work together to avoid prolonged intensive care hospitalizations. Although home care and hospital care are reimbursed through separate revenue streams, a global accounting may demonstrate that higher home nurse reimbursement provides an overall cost savings. Alternatively, transitional care programming may provide a more cost-effective option for families and health care systems when discharge hurdles are nonmedical. Several of the patients in this cohort were initially discharged to transitional care while awaiting home nursing assignment, which significantly decreased their acute-care LOS. However, transitional care beds are limited within the state. Expanding the role of these centers may improve health care efficiency.

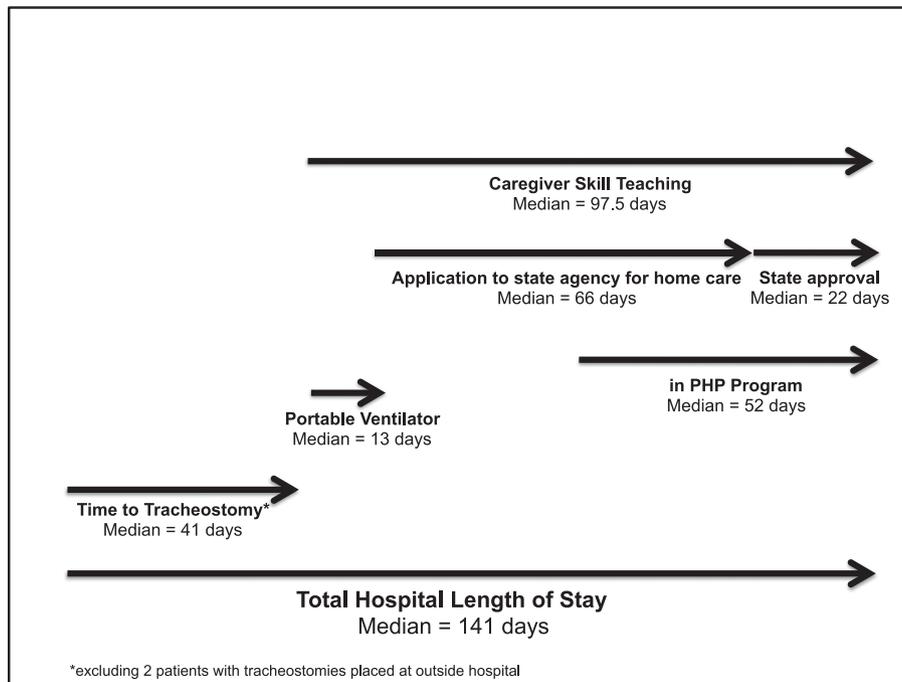
A few prior studies have examined factors for prolonged hospital LOS. In 1993, at Children's Hospital Los Angeles, initial hospital stays for ventilated children were reported to average 172 days.⁴ In 2003, in the United Kingdom, a cohort of children were discharged from the hospital with a ventilator after a median of 293 days.⁵ A recent study from Baylor College of Medicine reported an average LOS of 81.5 days.¹⁰ Our LOS of 52 days after medical stabilization and PHP transfer compares favorably with these findings, as does our total hospital LOS of 141 days.

Additionally, a recently published study by Baker et al demonstrated the impact of a standardized discharge process with an interdisciplinary team for ventilator-dependent children. In this quality improvement intervention, LOS decreased dramatically without resultant increase in emergency department admissions, readmissions, or mortality.¹¹ This important work adds to our overall understanding that

TABLE 1 Timeline for discharge for children in PHP (*n* = 23)

Discharge Timeline	<i>n</i>	Median days (25th, 75th percentile)
Total hospital length of stay (LOS)	23	141 (68, 177)
Discharge location		
Discharged to home	15	142 (109, 177)
Discharged to transitional care center or different hospital	8	106 (54.5, 199)
Prematurity status		
Premature	9	171 (140, 198)
Not premature	14	132 (63, 146)
Medical factors		
LOS after tracheostomy placement	21	105 (56, 127)
LOS after transfer to PHP Program	23	52 (29, 65)
Time to portable ventilator after tracheostomy ^a	21	13 (9, 50)
DSCC approval process		
Total time from tracheostomy to DSCC waiver approval ^a	20	114.5 (84.5, 151)
Time to letter of medical necessity sent ^a	21	23 (7, 36)
Time from letter of medical necessity sent to full DSCC packet sent to capital ^a	20	66 (34, 87.5)
Time from DSCC waiver sent to capital to approval received ^a	20	22 (16, 26)
Primary and secondary caregiver education		
Time to primary caregiver skill teaching completed ^a	18	97.5 (44, 114)
Time to secondary caregiver skill teaching completed ^a	18	94.5 (53, 117)
Time to caregiver independence demonstrated ^a	18	97.5 (74, 137)

^a For calculation of displayed intervals, time 0 was considered the day of tracheostomy placement.



PHP= Pulmonary Habilitation Program

FIGURE 2 Timeline for discharge after new tracheostomy.

standardizing family-centered discharge preparations is crucial to improving health care quality for this medically complicated population.

There are several limitations to this study. First, it was completed at a single site working mostly within a single state system, and thus may not be generalizable to the overall national population. Second, although the cohort represents 100% of the patients with first-time discharges with home ventilation from the largest children's hospital in the Chicagoland area, the cohort available for analysis was small.

CONCLUSIONS

Analyzing our future data will enable our team to assess the success of initiating earlier DSCC applications and family training. Additionally, it is not known what impact unpredictable and fluctuating state revenue streams may have on inpatient LOS for children with mechanical ventilation; however, ongoing data collection may help to estimate the effect of understaffing and budget cuts for home nursing programs.

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