Hospital Discharge of Respiratory-Technology-Dependent Children: Role of a Dedicated Respiratory Care Discharge Coordinator

Donna K Tearl CRT, Timothy J Cox RRT, and James H Hertzog MD

BACKGROUND: Preparation of respiratory-technology-dependent children for hospital discharge presents many challenges. Adequate training and education of parental caregivers, discharge planning, and coordination with the durable-medical-equipment and home-nursing companies must be completed. A process using multiple respiratory therapists (RTs) to achieve this may not be efficient. METHODS: We evaluated our model, in which a dedicated RT discharge coordinator provides education and coordinates discharge planning of respiratory-technology-dependent pediatric patients. This system provides a single contact for caregivers and outside agencies, a single respiratory-care educator for the caregivers, and a clinical pathway that involves the entire multidisciplinary team. Patient length of stay and customer satisfaction were evaluated before and after implementation of the discharge-coordinator program. RESULTS: Our dedicated-RT-discharge-coordinator model was associated with rapid initiation of frequent family-training sessions. Durable-medical-equipment-company personnel reported that they had increased satisfaction with the quality of training of the family caregivers. The members of the hospital multidisciplinary team had increased satisfaction with the discharge process. Patient length of stay nonsignificantly decreased after the implementation of the discharge-coordinator program. CONCLUSIONS: There are several advantages to using a dedicated RT-discharge-coordinator system for home-discharge preparation of respiratory-technology-dependent children. *Key words: customer satisfaction, home mechanical ventilation, hospital discharge, respiratory care, technology-dependent children*. [Respir Care 2006; 51(7):744–749. © 2006 Daedalus Enterprises]

Introduction

Over the past 2 decades there has been a dramatic increase in the number of infants, children, and adolescents with respiratory failure who receive long-term mechanical ventilatory support via tracheostomy.[1–4] Increasing importance has been placed on discharging these children to their homes rather than continuing hospital care. Home care can be a medically safe alternative to prolonged hospitalization.[1,5–9] The home environment improves the quality of life for the child and family, and promotes the child's developmental growth.[4,6,10,11] A significant reduction in health-care expenses may also be realized.[5] Because of the medical complexity of these cases and the need to coordinate multiple health-care professionals for home care, the discharge process can be complicated and challenging.[1–3,7,9] The transition to home care can produce substantial stress for the family of the respiratory-technology-dependent child,[9,12] which makes adequate planning for support of the family at home all the more important.

Our experience reflects the trend favoring the home discharge of respiratory-technology-dependent children. Between January 1999 and December 2001, 74 respiratory-technology-dependent infants and children were discharged from our hospital to home for the first time with technological support. In response to the increasing number of patients who require preparation and planning for

Donna K Tearl CRT and Timothy J Cox RRT are affiliated with the Department of Respiratory Care Services; James H Hertzog MD is affiliated with the Department of Anesthesiology and Critical Care Medicine, Nemours Children's Clinic-Wilmington, Alfred I duPont Hospital for Children, Wilmington, Delaware.

Donna K Tearl CRT presented a version of this report at the 48th International Respiratory Congress of the American Association for Respiratory Care Congress, held October 5–8, 2002, in Tampa Bay, Florida.

Correspondence: Donna K Tearl CRT, Department of Respiratory Care Services, Alfred I DuPont Hospital for Children, 1600 Rockland Road, PO Box 269, Wilmington DE 19899. E-mail: dtearl@nemours.org.

home discharge with respiratory-technology support, we developed a practice model in which a dedicated respiratory therapist (RT) discharge coordinator provides education to the families of respiratory-technology-dependent children and coordinates discharge planning. We examined the impact of this model on our practice. We hypothesized that this model would shorten our patients' hospital stays and increase the satisfaction of the other health-care professionals in the discharge process.

Methods

Our institutional review board reviewed our protocol and waived the requirement for informed patient consent.

Before June 2000, at our institution, multiple RTs provided education to the families of respiratory-technology-dependent children. These activities were performed during an RT's regular ward-based work shift. Physicians identified patients in need of home-discharge preparation after initial medical stabilization, and notified the RT on duty during that shift. The RT recorded the patient's name onto a centralized board so that all staff were aware of the children and families in need of training. The director of respiratory care services subsequently assigned a primary RT to each child. The number of primary RTs ranged from 8 to 12 at any given time. The primary RT's job was to oversee the training provided to the family by the ward-based RT, to complete a demographic database, and to prepare a list of home-respiratory-care equipment for the social worker. Depending on the child's length of stay, as many as 20 RTs would provide training to the family. Education sessions might be cancelled, depending upon the clinical demands placed on the RT during any given shift. In addition, there were no established guidelines for the discharge-planning process. A multidisciplinary team, including a physician, a nurse, a social worker, representatives from therapeutic and nutritional services, and an RT, accomplished discharge planning on a case-by-case basis.

In June 2000, a dedicated RT discharge coordinator position was created. This position is filled by one individual, who carries no other responsibilities. Patients are identified by the RT discharge coordinator through ongoing evaluation of the patient population in critical-care areas of the hospital.

We developed a clinical pathway (Fig. 1) to guide the multidisciplinary team in proactive discharge planning. This pathway outlines a 10-week period in which to accomplish family education and discharge preparation with outside agencies. Training manuals were developed as an educational adjunct for families. Training progresses through the clinical pathway based on the family's comfort level, ability to perform procedures, and ability to use equipment, so the pathway can be completed in less than

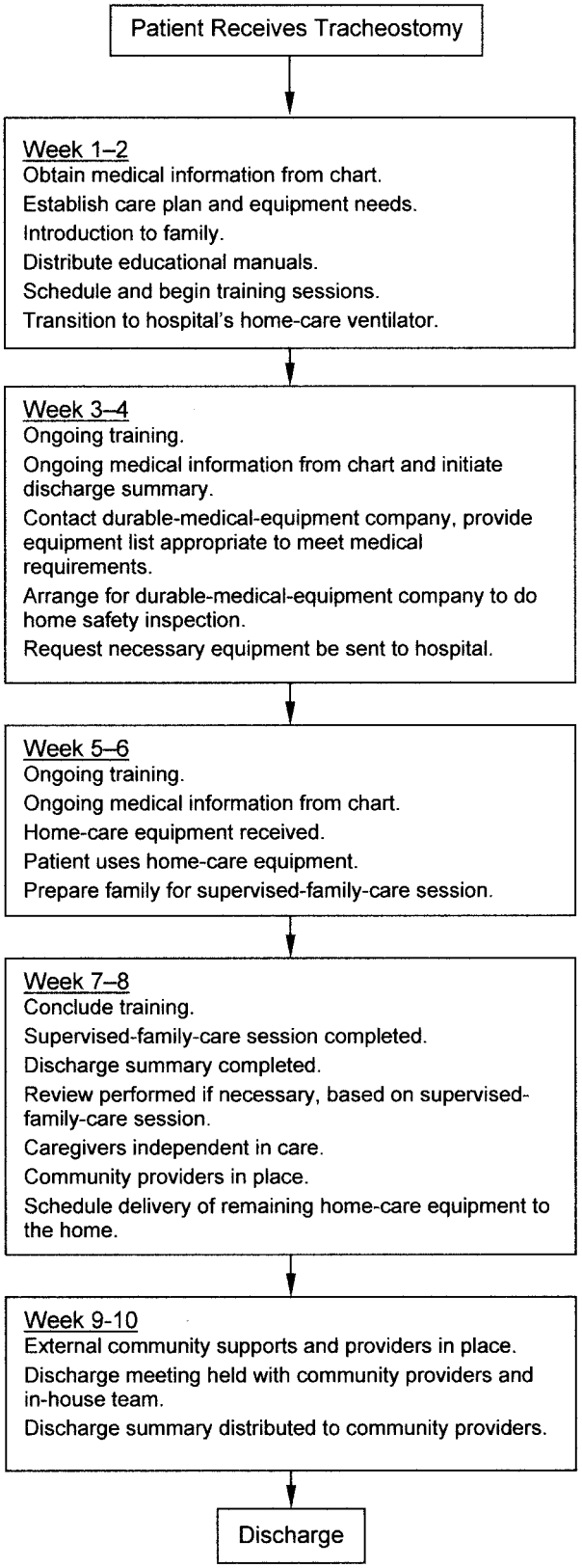

Fig. 1. Clinical pathway for discharge to home care for pediatric patients who need ongoing respiratory-technology support.

Table 1. Pre-Home-Discharge Respiratory-Care-Education Requirements for Family Caregivers

Airway Management (routine and emergency)
Independently demonstrate 3 tracheostomy tube changes
Manage tracheal decannulation
Manage tracheostomy tube obstruction
Tracheostomy Care
Demonstrate stoma and skin assessment and care
CPR
Complete CPR training, with modifications for tracheostomy
Manual Ventilation
Demonstrate knowledge of indications and precautions for manual resuscitator
Demonstrate proper use of manual resuscitator
Suctioning
Demonstrate proper suctioning technique
Demonstrate proper operation of suction equipment
Perform assessment before and after suctioning
Oxygen
Demonstrate knowledge of indications for oxygen therapy, oxygen safety, and maintenance of oxygen systems
Demonstrate proper use of oxygen with manual resuscitator and appropriate equipment
Pulse Oximetry
Demonstrate knowledge of indications for pulse oximetry
Demonstrate operation of pulse oximeter
Emergency Bag
Demonstrate knowledge of the indications for an emergency bag and the appropriate equipment required for patient portability
Chest PT
Demonstrate knowledge of indications, hazards, and precautions for chest physical therapy
Demonstrate proper administration of chest physical therapy
Ventilator
Demonstrate knowledge of principles of operation, components, power sources, alarm systems, monitoring variables, and methods of weaning support
Demonstrate proper operation of the external battery and charger
Nonventilator CPAP System
Demonstrate knowledge of principles of operation, components, power sources, alarm systems, monitoring variables, and methods of weaning support
Demonstrate proper operation of the external battery and charger
Tracheostomy Collar
Demonstrate knowledge of principles of operation, components, power sources, alarm systems, monitoring variable, and methods of weaning support
Demonstrate proper operation of the external battery and charger
Successfully complete supervised family care session

CPR = cardiopulmonary resuscitation
CPAP = continuous positive airway pressure

the allotted 10 weeks. We also created a document that lists the educational requirements to be completed by the caregivers, and each objective is "signed-off" after successful completion (Table 1). Criteria for discharge to home include achieving medical stability, caregiver completion of all training, independence in all aspects of the child's care, a successful supervised family care session for a total 24-hour period, and the presence of community support to allow transition to a safe home environment.

The discharge coordinator's role in the first 2 weeks of the pathway is to obtain medical information, establish a respiratory care plan, determine equipment needs, transition the patient to home-care equipment as appropriate, provide training manuals for education, and schedule training sessions. An initial family meeting is held in which the education and discharge processes are outlined.

During the third and fourth weeks, while education continues, contact is made with the durable-medical-equipment (DME) companies, to which the discharge coordinator provides the equipment list. Additional family meetings are scheduled to monitor family-education progress.

Over the next 4 weeks, education is completed and the family is prepared to perform a supervised family care session at the hospital, with health-care providers readily

available should questions or an emergency arise. This session has the family demonstrate their ability to independently perform all aspects of their child's care. The session can be divided into multiple sessions, but a total of 24 hours of care must be completed by the family caregivers. Final preparations for discharge are made with the DME companies and home nursing agencies, and a discharge meeting is held a few days before discharge to assure that preparations for home care are complete. Patients and their families are provided with a minimum of 16 hours a day home nursing care after discharge.

Demographic data on respiratory-technology-dependent patients are prospectively collected. Before July 2000, a written database was maintained. Subsequently, a computerized relational database has been used.

Information gathered during the study period included patient age, diagnosis, type of equipment used, hospital length of stay, number of training sessions the family undertook, and number of days elapsed from the identification of a patient in need of discharge services to the initiation of family training.

We surveyed both the DME-companies' personnel's satisfaction with the quality of family-caregiver training and the hospital's multidisciplinary team member's satisfaction with the discharge coordinator's performance as educator of the families. The DME surveys were conducted over the telephone or via facsimile, with each DME company's director of respiratory care. A positive response was recorded when the DME company's director of respiratory care noted no deficiencies in the family's knowledge or performance or in the equipment selected for use, whereas a negative response was recorded if there were any such deficiencies.

During the period January 1999 through May 2000, before the discharge coordinator began services, 7 DME companies were used to provide services to the 25 children discharged to home during that period. Surveys were completed for 19 of the 25 children. During the period June 2000 through December 2001 (the first 17 months of the discharge-coordinator program), 9 DME companies were used to provide services to the 49 children discharged to home during that period. Surveys were completed for all 49 children. Specifically, DME-company personnel were asked whether the family requested assistance or the DME representative observed deficiencies in the family's knowledge of home equipment (such as ventilators, self-inflating resuscitators, or nebulizers) or procedures related to equipment (such as suctioning or ventilator-circuit changes) during the first month after discharge. They were also asked whether the equipment chosen for home care best suited the patient's needs.

Multidisciplinary team members were asked to evaluate (on a 5-point Likert scale) the discharge coordinator's availability for training sessions and discharge meetings, the quality and timeliness of family education, and the quality of communication. These surveys were mailed to the multidisciplinary team members by the hospital's director of respiratory care. This group of 17 individuals included physicians, nurse managers, and social workers. The same individuals were surveyed before and after the initiation of the discharge-coordinator position, and we had a response rate of 100%.

The before-and-after differences in patient demographics and survey responses were compared using Student's *t* test, the Mann-Whitney *U* test, and chi-square analysis. A p value < 0.05 was considered statistically significant.

Results

From January 1999 through December 2001, 74 respiratory-technology-dependent children were discharged from our hospital to home for the first time with respiratory-technology support. Data were available for all 74 patients.

Table 2 shows the patient age groups, diagnoses, and respiratory equipment used by the home-discharge patients during the 36-month period of January 1999 through December 2001, and before and after the dedicated-RT discharge coordinator began services, in June 2000. There were no statistically significant differences in age ($p = 0.128$), diagnosis ($p = 0.142$), or equipment ($p = 0.426$) between the 2 periods.

The mean ± SD hospital length of stay was 82 ± 45 days before the implementation of the program, and after implementation it was 48 ± 44 days ($p = 0.06$ via Student's *t* test).

Table 3 shows the results of the surveys of DME-company personnel. After the institution of the discharge-coordinator program there were statistically significant increases in the number of times that DME-company personnel (1) did not receive family requests for assistance with home equipment, (2) did not note inadequate family knowledge of home equipment, (3) did not note deficiencies in family performance, and (4) did find that the home equipment selected best suited the patient ($p < 0.001$). After implementation of the program, multidisciplinary team members had increased satisfaction with the discharge process ($p < 0.001$).

After implementation of the program, the average number of training sessions held per family, in sequential 6-month periods, was 7 (July through December 2000), 5 (January through June 2001), and 10 (July through December 2001). The number of days between patient-identification and the beginning of family training during those periods was 9 days, 8 days, and 9 days, respectively.

Table 2. Patient Age Groups, Diagnoses, and Respiratory Equipment Used

	Total	Before* (Jan 1999-May 2000)	After† (Jun 2000-Dec 2001)	Statistical Comparisons
Number of patients	74	25	49	NA
Age Group				p = 0.128
0–6 months	18	2	16	
7–12 months	13	7	6	
13–24 months	7	2	5	
25–48 months	9	3	6	
> 48 months	27	11	16	
Diagnosis				p = 0.142
Airway obstruction	27	6	21	
Neuromuscular/SCI	24	11	13	
BPD	23	8	15	
Equipment				p = 0.426
Ventilator	40	17	23	
CPAP	24	6	18	
Tracheostomy collar	4	1	3	
NPV	3	1	2	
BiPAP	3	0	3	

*Before implementation of the pediatric respiratory-care discharge coordinator system.
†After implementation of the pediatric respiratory-care discharge coordinator system.
NA = not applicable
DF = degrees of freedom
SCI = spinal-cord injury
BPD = bronchopulmonary dysplasia
CPAP = continuous positive airway pressure
NPV = negative-pressure ventilator
BiPAP = bi-level positive airway pressure

Table 3. Survey Responses From Durable-Medical-Equipment-Companies' Personnel Regarding Perceived Family Readiness for Discharge

Perceived Readiness	Before* (Jan 1999-May 2000)	After* (Jun 2000 - Dec 2001)	Total
Positive (no deficiencies noted)	12	45	57
Negative (deficiencies noted)	7	4	11
No response	6	0	6
Total†	25	49	74

*Before versus after implementation of the pediatric respiratory-care discharge-coordinator system.
†Group comparison: chi square = 20.272, degrees of freedom = 2, $p < 0.001$

Discussion

The number of children receiving long-term, life-sustaining respiratory-care support is substantial and increasing. Preparing these children for discharge to home for the first time with respiratory-technology support is challenging for health-care workers and families. Though medical reasons may delay the hospital discharge of these children, nonmedical issues are common obstacles.[1]

Other clinicians have published their experiences with preparing patients for discharge to home with technological support. In the United Kingdom, Jardine and Wallis formulated guidelines for preparation for home discharge of children requiring long-term mechanical ventilatory support.[2] Central to their process is having a single individual responsible for coordinating the team involved in the child's discharge. A similar process for adult patients requiring long-term mechanical ventilation was described by Ambrosino and Vianello.[4] Warren et al[13] developed a discharge-planning program for their adult patients with new tracheostomies in response to their need for improved intensive-care-unit utilization. Similar information for infants was presented by Fiske.[14] However, none of these reports examined the impact of their programs on hospital length of stay or the satisfaction of the caregivers with the discharge process. Rozell and Newman[15] presented a discharge-planning critical pathway for their mechanically ventilated adult patients, in which discharge is achieved in 21 days. A major difference between their program and ours is that a nurse is present in the home for only the first 2 days, after which daily visits occur for a limited period. Family members must quickly become the primary 24-hour-a-day caregivers, which we consider impractical for

the care of children who require respiratory-technology support. Rozell and Newman did not provide any information as to whether discharge in 21 days is actually achieved.

The satisfaction of the multidisciplinary hospital team members with communication, family education, and the discharge process was significantly improved, and these improvements probably make the discharge process more efficient and timely. Length of stay nonsignificantly decreased after the implementation of the program. Other factors that might affect the length of stay were not evaluated, so additional study of this issue would be valuable.

DME-company personnel reported significant improvement in the choice of home equipment and the family's ability to use the equipment and perform the care procedures. This suggests improved caregiver competence as a result of the focused education provided by the dedicated RT discharge coordinator. After the institution of the discharge-coordinator program, families in need of education and discharge planning were identified in less than 10 days, and formal training sessions were held every 5–10 days throughout the course of the hospital stay. Greater caregiver skill in the technological aspects of the care would probably lead to a safer home environment for the patient and less family stress.

We did not formally survey the family's satisfaction with the discharge process or the families' perceived level of preparedness and stress in the home environment, and further evaluation of these issues is needed.

Another limitation of our analysis is that we evaluated only a relatively small number of patients, at one center. This may limit the applicability of our findings to other centers with different patient populations. However, we believe our results provide initial insights into the issues discussed.

Conclusions

New technology in respiratory equipment allows medical management to progress quickly. Our model of a dedicated RT discharge coordinator—who facilitates early family identification, home-care equipment application, and institution of family education—allows ample time for family preparation and eases the transition to the home environment. It also assures that training is accomplished in a consistent and thorough fashion and that communication among all parties is timely and accurate. Ongoing evaluation and refinement of this system will help improve the complicated but beneficial process of bringing children with respiratory-technology needs home to their families.

REFERENCES

1. DeWitt PK, Jansen MT, Ward SL, Keens TG. Obstacles to discharge of ventilator-assisted children from the hospital to home. Chest 1993; 103(5):1560–1565.
2. Jardine E, Wallis C. Core guidelines for the discharge home of the child on long-term assisted ventilation in the United Kingdom. UK Working Party on Paediatric Long Term Ventilation. Thorax 1998; 53(9):762–767.
3. Jardine E, O'Toole M, Paton JY, Wallis C. Current status of long term ventilation of children in the United Kingdom: questionnaire survey. BMJ 1999;318(7179):295–299.
4. Ambrosino N, Vianello A. Where to perform long-term ventilation. Respir Care Clin N Am 2002;8(3):463–478.
5. Hazlett DE. A study of pediatric home ventilator management: medical, psychosocial, and financial aspects. J Pediatr Nurs 1989;4(4): 284–293.
6. Fields AI, Coble DH, Pollack MM, Kaufman J. Outcome of home care for technology-dependent children: success of an independent, community-based case management model. Pediatr Pulmonol 1991; 11(4):310–317.
7. Noyes J, Hartmann H, Samuels M, Southall D. The experiences and views of parents who care for ventilator-dependent children. J Clin Nurs 1999;8(4):440–450.
8. Kamm M, Burger R, Rimensberger P, Knoblauch A, Hammer J. Survey of children supported by long-term mechanical ventilation in Switzerland. Swiss Med Wkly 2001;131(19–20):261–266.
9. Sakakihara Y, Yamanaka T, Kajii M, Kamoshita S. Long-term ventilator-assisted children in Japan: a national survey. Acta Paediatr Jpn 1996;38(2):137–142.
10. Allen NL, Simone JA, Wingenbach GF. Families with a ventilator-assisted child: transitional issues. J Perinatol 1994;14(1):48–55.
11. Mentro AM, Steward DK. Caring for medically fragile children in the home: an alternative theoretical approach. Res Theory Nurs Pract 2002;16(3):161–177.
12. Kirk S. Families' experiences of caring at home for a technology-dependent child: a review of the literature. Child Care Health Dev 1998;24(2):101–114.
13. Warren ML, Jarrett C, Senegal R, Parker A, Kraus J, Hartgraves D. An interdisciplinary approach to transitioning ventilator-dependent patients to home. J Nurs Care Qual 2004;19(1):67–73.
14. Fiske E. Effective strategies to prepare infants and families for home tracheostomy care. Adv Neonatal Care 2004;4(1):42–53.
15. Rozell BR, Newman KL. Extending a critical path for patients who are ventilator dependent: nursing case management in the home setting. Home Healthc Nurse 1994;12(4):21–25.