Home Discharge of Technology-Dependent Children: Evaluation of a Respiratory-Therapist Driven Family Education Program

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BACKGROUND: Initial hospital discharge to home of technology-dependent children requires extensive training and education of the family caregivers. Education of adult family members should promote positive interactions in a nonthreatening manner while facilitating the development of the knowledge and skills to competently and independently provide all aspects of the medical care. We utilize a training program for adult family members of children who have undergone tracheostomy to facilitate long-term mechanical ventilatory support and who are being prepared for their initial discharge from the hospital to home. A dedicated respiratory therapist family educator directs this program. Multiple teaching tools, activities, and training sessions, based on adult learning theory, are utilized to develop appropriate clinical skills to manage children with tracheostomies and the associated technological supports. METHODS: We evaluated the effectiveness of our program by administering a written test to caregivers, at the start and the conclusion of their training. We also surveyed the caregivers about their satisfaction with the educational program and the respiratory therapist family educator's performance. We also surveyed employees of the durable medical equipment companies used by the families, regarding the caregivers' knowledge and competency in the home one month following discharge. RESULTS: Our program was associated with a statistically significant improvement in caregiver test performance, and the caregivers expressed a high degree of satisfaction with the program. The employees of the durable medical equipment companies perceived a high degree of knowledge and competence on the part of the home caregivers. CONCLUSION: Our training program appears to have a positive impact on the educational preparation of caregivers. *Key words: caregiver, education, adult learning, customer satisfaction, home discharge, respiratory care, technology-dependent children.* [Respir Care 2007;52(2): 171–176. © 2007 Daedalus Enterprises]

Introduction

The placement of a tracheostomy tube to facilitate long-term mechanical ventilation in infants, children, and adolescents with chronic respiratory failure has become increasingly common.[1–4] Because of the complexity of these children's conditions and the technological supports they require, as well as the nationwide shortage of home healthcare nurses able to care for these children, parents must participate in the home medical care and monitoring. Thus, extensive training and education of the adult caregivers must be completed prior to a child's discharge.[5–7]

Characteristics of adult learning include a reliance on accumulated life experiences and self-direction. Adult learning is commonly goal-directed and relevancy oriented.[8–11] Since adults are goal-oriented, an adult educational program should clearly outline the objectives and empha-

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size the importance of the learning and how the new knowledge will be of value. Consideration must be given to the individual factors that affect learning, including the learner's level of commitment, pre-existing knowledge, and ability to master relevant technology. The curriculum should focus on a high level of original learning, because if the adult learner does not learn the material well initially, then subsequent retention of the information will suffer. The adult caregiver also must be given the opportunity to link new information with previously attained knowledge and experience. Emphasis on critical concepts and repetitive, active participation add value to the learning. Critical elements of the learning process include motivation, reinforcement, retention, and transference.[9] Adult learners have many responsibilities, anxieties, and stresses, which can act as barriers to their ability to learn. The educational atmosphere should be friendly, respectful, and nonthreatening. Positive reinforcement and constant feedback can enhance learning.[9] An effective program will consider all these concepts in order to provide caregivers with a quality education.

Since 2000, we have offered a training program, directed by a designated respiratory therapist (RT), for the education of the parents of children with tracheostomies and technological supports who were being prepared for initial discharge from the hospital to home.[12] The educational approach of our program relies heavily upon the adult learning concepts previously outlined. Thus far, the caregivers of over 100 technology-dependent children have participated in our program. However, we had never objectively evaluated the impact of our program on caregiver education. Furthermore, minimal research on this topic has been published. We evaluated the effectiveness of our program with regard to caregiver knowledge acquisition prior to discharge, caregiver satisfaction with the educational program, and caregiver satisfaction with the designated RT family educator. We also surveyed employees of the durable medical equipment companies used by the families, regarding the caregivers' knowledge and competency in the home one month following discharge.

Methods

Our institutional review board reviewed our protocol and provided exemption to the requirement for informed consent from participants.

A comprehensive training program directed by a dedicated RT family educator was provided to the caregivers of children who had undergone tracheostomy for long-term mechanical ventilatory support.[12] Training was initiated as soon as 24 hours after placement of the tracheostomy tube. Early introduction to the RT family educator established a rapport to help prepare caregivers for the learning process and to provide reassurance that the experience would be nonthreatening. The educational process continued over the next 6–8 weeks and was individualized and based on the caregiver's educational needs and limitations, as determined weekly by the caregiver's return demonstration of skills and knowledge to the RT family educator. Repetition and positive reinforcement through practice and interactions occurred regularly. Training progressed based on the family's comfort level, ability to perform procedures, and ability to use equipment.

The educational materials consisted of an 84-page training manual with illustrations, visual aids such as anatomical charts and models, and home respiratory care equipment for use in interactive sessions with the caregivers and child. An infant manikin with a tracheostomy is used for initial hands-on practice sessions, allowing family caregivers to gain confidence in skill sets. A list of the educational requirements to be completed by the caregivers is reviewed with the caregivers at the start of training, and each objective is "signed off" after successful completion (Table 1). The RT family educator performs ongoing assessments of the caregivers' skill development, competence, and independence. At the conclusion of training, with successful completion of all educational requirements, a 24-hour supervised family care session is performed, during which the caregivers perform all aspects of their child's medical care and demonstrate their comfort levels, competence, and critical skills set while still in the hospital setting.

A 20-question, written, multiple-choice and true/false examination was administered to the caregivers at the start and conclusion of training to evaluate the impact of the training program on knowledge acquisition. The testing content focused on relevant pulmonary physiology, such as the need for warm humidification when the upper airway is bypassed with a tracheostomy tube; knowledge about technological supports, such as the liter flow of oxygen to use with a manual ventilator and the importance of the ventilator's low-pressure alarm; and emergency interventions, such as the response to low pulse oximetry measurements and the list of equipment that must always be available to their child. The initial and final test scores were analyzed with the Wilcoxon signed rank test. A p value ≤ 0.05 was considered statistically significant.

Before the test was administered to any of the caregivers, it was administered to 10 RTs who were not directly involved in the training program. This established that the test had a degree of difficulty that could demonstrate improvement in test performance, and thus eliminate the "floor-ceiling" effect on scoring. Furthermore, testing the RTs established a comparative score from a group of respiratory care professionals who are not routinely involved in home care.

Caregivers were asked to evaluate the RT family educator and their overall satisfaction with their education at

Table 1. Respiratory Education Items That Must Be Completed by the Caregivers Before Discharge to Home

Airway Management: Routine and Emergency
Demonstrate tracheostomy tube changes (3 independently)
Manage tracheal decannulation
Manage tracheostomy tube obstruction
Tracheostomy Care
Demonstrate stoma and skin assessment and care
Cardiopulmonary Resuscitation
Complete cardiopulmonary resuscitation training, with modifications for tracheostomy
Manual Ventilation
Demonstrate knowledge of indications for and precautions with manual resuscitator
Demonstrate proper use of manual resuscitator
Suctioning
Demonstrate proper suctioning technique
Demonstrate proper operation of suctioning 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 Physical Therapy
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 Continuous Positive Airway Systems
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 variables, and methods of weaning support
Demonstrate proper operation of the external battery and charger
Successfully complete supervised family care session

the end of their training, by responding to 8 statements, with regard to what they would expect from an ideal RT family educator and what they actually experienced. The survey used a 5-point Likert scale: 1 = strongly disagree, 2 = disagree, 3 = neutral, 4 =agree, and 5 = strongly agree (Table 2). A ninth statement surveyed their overall satisfaction with the education provided by the RT family educator. This evaluation was incorporated into a general evaluation of the respiratory care department and was administered and analyzed by the hospital's quality assessment department, independent of the RT family educator.

Additional outcome assessments were performed by surveying the respiratory care directors of the durable medical equipment (DME) companies that the caregiver families hired to provide the respiratory equipment and supplies. The DME company RT routinely visits the family daily for the first 2 weeks following discharge and reviews the caregivers' knowledge and skills related to the home care of ventilator-dependent children, and provides additional instruction as deemed necessary per the DME company's standards. The survey of the DME company employee is conducted 1 month after the child's discharge to home, and it evaluates the DME company respiratory care director's impression of caregiver knowledge and competency in home respiratory equipment and procedures. Specifically, the DME company's personnel were asked whether the family requested assistance or the DME company representative observed deficiencies in the family's knowledge of home equipment (such as ventilator, self-inflating resuscitator, or pulse oximeter) or procedures related to

Table 2. Caregiver Survey Statements for Likert Scoring

The Respiratory Therapist Educator:
1. Provides thorough training and education in a timely fashion
2. Gives my child and the caregivers reasonable attention
3. Listens carefully to the child and caregivers being trained
4. Explains things in a way we can understand
5. Answers our questions
6. Has accurate information about my child's discharge planning
7. Is caring and understanding
8. Spends the right amount of time with us
9. Overall, I am satisfied with the education the respiratory therapist provided

equipment (such as suctioning or ventilator circuit changes). They were also asked if the equipment chosen for home care best suited the patient's needs. A positive response was recorded when no deficiencies were noted in the family's knowledge or performance, and a negative response was recorded if any deficiencies were noted. Five different DME companies provided service to the 20 caregivers evaluated during our study period, and the surveys were completed in all cases.

Results

From January 2004 to December 2004, we surveyed and evaluated 20 caregivers (for 10 children) who had undergone the training program for the first time. Data were collected from all the caregivers.

There were statistically significant improvements between the caregivers' pre-training and post-training test scores (Wilcoxon signed rank $Z = -3.84$, $p = 0.001$). The mean ± SD pre-training test score was 35.3 ± 13.2%, as compared with the post-training mean test score of 91.1 ± 4.9%. By comparison, for the 10 RTs who took the same test, the mean ± SD score was 86.7 ± 4.9%.

Table 3 shows the Likert score results from the caregiver survey. The RT family educator met or exceeded the expectations for an ideal educator in all categories except for having accurate information about the child's discharge plans. Table 3 also shows the percentage of caregivers who assigned a Likert score of 4 (agree) or 5 (strongly agree) for the 8 statements pertaining to the RT family educator. The caregiver's Likert score for overall satisfaction with the education provided by the RT educator (statement 9) was 4.94.

The survey responses from the DME company employees indicated 100% satisfaction with caregiver competency. There were no incidents recorded by the DME company employees of a caregiver requesting assistance with home equipment. There was no noted inadequacy in the caregivers' knowledge of home equipment and no noted deficiencies in family performance. The home equipment selection was thought to be best suited for the patient.

Table 3. Likert Score Results for an Ideal Versus the Actual Respiratory Therapist Educator

	Likert Score		Percent of Actual Who Strongly Agreed	Percent of Actual Who Agreed
	Ideal	Actual		
Timely	4.83	4.83	92	0
Attentive	4.75	4.92	92	8
Listens	4.83	4.83	83	17
Explains	4.75	4.75	83	8
Answers questions	4.83	4.83	92	0
Accurate information	4.83	4.75	75	25
Caring, understanding	4.75	4.83	83	17
Spends time	4.83	4.83	83	17

Discussion

Children who receive tracheostomies to facilitate long-term mechanical ventilatory support face many barriers to discharge from the hospital to home. Because of the complexities of their medical care and the unavailability of constant home nursing care in most situations, adult caregivers must participate in the medical care of their child and understand the technological supports their child needs. As a result, there is a need to provide education and training to these adults prior to the discharge of their child to home.

There are multiple challenges in the training of adult caregivers because of their diversity. Each individual has unique needs and learning styles. Emotions, social concerns, and anxiety can be barriers that negatively affect one's ability to learn.[8–11] Overcoming individual differences and barriers requires an organized and thoughtful educational approach. Adult learners expect to be treated with respect and will learn better in a nonthreatening environment with an individual with whom they have an established rapport. Relationships need to be developed to better understand the individual's strengths and weaknesses. Good educational programs incorporate activities for all learning styles and utilize a variety of teaching tools, such as visual aids, illustrations, and active participation to reinforce critical concepts.[8–11] Educational goals should be clearly defined for adults to achieve these goals.

Despite the increasing numbers of caregivers of technology-dependent children, few data are available about the effectiveness of pre-hospital-discharge caregiver education on home care of these children. Both Hill[13] and Lewarski[14] noted the importance of an early teaching phase in the discharge plan and cited subject matter that ideally

should be taught and several available teaching guidelines, but until now there has been no information about the impact of educational programs in preparing adult caregivers. Bakewell-Sachs and Porth noted the importance of the family's confidence and competence in the care of their child prior to discharge and the need for early and progressive training, but, again, they provided no information on the success of the education program.[15] Hotaling et al[16] used a checklist format to guide pre-discharge education of adult caregivers. When caregivers were surveyed as to whether they felt prepared to take their child home from the hospital, 80% agreed, whereas 14% somewhat agreed and 6% somewhat disagreed. To our knowledge, no other information has been published on the effectiveness of pre-discharge education programs for adult caregivers of technology-dependent children.

We previously evaluated our program in which a designated RT family educator prepares the caregivers of technology-dependent children for initial hospital discharge.[12] In comparison with our previous approach, in which multiple RTs participated in the education and discharge process, we found that a system with one dedicated RT family educator was associated with a rapid initiation of frequent family-training sessions, greater satisfaction with the discharge process among members of the hospital's multidisciplinary health-care team and DME-company personnel, and greater satisfaction among DME-company personnel with the quality of caregiver training. We had not, however, attempted to directly measure the extent to which educational goals had been attained or the caregivers' satisfaction with the program. The present study addresses these issues. Our results support our belief that the training program is achieving its goal of caregiver preparation. There was a statistically significant improvement in caregiver test scores after the training. Of interest, the caregivers' performance on the post-training test was similar to that of the 10 RTs, which suggests that the caregivers achieved a high level of understanding. Further evidence that caregiver preparation was achieved by our training program is provided by the results of the DME-company employee survey. They reported satisfaction with the caregivers' knowledge of and ability to use respiratory equipment and to perform the necessary technological procedures.

The results of the caregivers' survey suggest that our training program met their adult learning needs. Caregivers reported very positive experiences with both the designated RT family educator and the quality of the education that was provided. Their responses suggest that the training was thorough and timely and that the RT family educator had accurate information and the ability to give appropriate amounts of attention and time to the caregivers. In addition, the caregivers were satisfied with the RT family educator's interpersonal skills with respect to listening, caring, and understanding. The program's content was presented in a manner that the caregivers felt they could understand, and the session duration was felt to be appropriate. The caregivers perceived that they had achieved a level of preparedness and confidence needed for initial discharge. The only category in which the RT educator did not meet or exceed the caregivers' expectations for an ideal RT educator was that of having accurate information about their child's discharge planning. This impression may be in part because factors such as the child's medical condition and the availability of home-care resources affect the discharge plan and may change unpredictably and in ways that cannot be controlled by the RT educator.

There are limitations to our study. A relatively small number of caregivers were studied, at a single institution, which limits the applicability of our findings related to our specific training program to other centers with different educators and caregivers. Furthermore, we evaluated only the short-term impact of our education program. We did not evaluate whether caregiver knowledge and performance deteriorate after 1 month following discharge. We chose to administer a written, multiple-choice examination to evaluate knowledge acquisition because of the convenience of this testing method, the general familiarity with written testing, and the objective measurement that is obtained by this method. Other testing modalities, such as verbal testing or testing with a human simulation model, might provide a better evaluation of knowledge acquisition in terms of converting knowledge into demonstrable actions, but such tests can be difficult to objectively measure, and they require additional resources for testing. Either testing approach can be associated with substantial anxiety for the test-taker and can be biased against caregivers who have lower educational attainments or less familiarity with the testing method. Our caregivers' marked improvement in test scores suggests that this issue did not come into play during our study. Despite these various limitations, our findings provide initial insights into the process of successful training of families for participation in the care of their technology-dependent children at home.

Conclusions

Our model of a dedicated RT family educator, who provides education to family caregivers, using a multitude of educational materials, visual aids, and interactive sessions, promotes caregiver learning. Ongoing evaluation and refinement of training programs that prepare families for the discharge of their technology-dependent children to home should be performed to identify new opportunities for improvement in this process.

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