

Paving a Road Home: Developing Education for a Pediatric Home-Going VAD Program

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Presented at the 15th International Conference on Pediatric Mechanical Circulatory Support Systems and Pediatric Cardiopulmonary Perfusion, New York City, New York, May 9, 2019.

Abstract: The objective was to create a multidisciplinary education plan for discharge home following implantation of a ventricular assist device (VAD) in pediatrics. Educational program was developed for the local community: emergency department, emergency medical services, medical transport team, as well as, the pediatric patient and their caregivers. Education geared to the individual learner included both lecture and hands-on training. A direct line for family and local providers to speak directly with a VAD-trained physician 24/7 was also created. Patient and caregivers required to 1) perform 10 supervised power exchanges; 2) qualify written quizzes on the controller, battery charger, alarms, and troubleshooting; 3)

perform 10 supervised dressing changes; 4) pass simulation session responding correctly to alarm scenarios; and 5) take both an on-campus and off-campus field trip unaccompanied by support staff. Once the education plan is complete and the patient is medically stable, they are considered ready for discharge. From a mechanical support perspective, discharge home of a medically complex pediatric patient on a durable VAD can be accomplished safely, even in a low volume center, with attention to detail, creation of a robust education plan, and close partnership between the VAD team, the family, and the community. **Keywords:** pediatrics, ventricular assist device, heart failure, discharge. *J Extra Corpor Technol. 2019;51:248–54*

OVERVIEW

With new developments in device manufacturing, software, and management, continuous flow durable ventricular assist devices (VADs) are now a viable consideration for many smaller pediatric patients, including those with complex congenital heart disease (1,2). As more patients continue to wait longer for the limited resource of donor organs (3) and more patients are considering the utility of destination VAD therapy, there is an increasing need to support pediatric patients with VADs at home.

Pediatric VAD discharge rates range from 12% in single center reports to 55% from registry data from Pediatric Interagency Registry for Mechanical Circulatory Support (Pedimacs) (4,5). In comparison, adult VAD discharge rates may be as high as 87% in single-center studies (6). Although adult centers have a history of discharging VAD patients, applying that experience directly to the pediatric population does not encompass all scenarios. For example, educating adult caregivers can become cumbersome if the child lives in different households because of divorce or is in the care of multiple extended family members. One must also consider a child returning to school, as education must also be provided to the school nurse, teachers, and principal. The education plan must incorporate information and learning styles tailored to the age and maturity of the child, as well as the caregivers. Important non-medical factors for a successful discharge include 1) steady home environment, 2) committed family support, and 3) ease of partnership with local emergency medical and transportation teams. Our

Received for publication June 6, 2019; accepted October 7, 2019.
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The senior author has stated that the authors have reported no material, financial, or other relationship with any health-care-related business or other entity whose products or services are discussed in this article.

institution has worked to create a multidisciplinary program to educate pediatric patients, and caregivers, along with the community in their local area, with a goal of a safe discharge home on a VAD.

DESCRIPTION

First Steps: Team Building, Educational Plan, and Patient Selection

Collaboration with regional adult and pediatric VAD colleagues who are experienced with VAD discharge proved to be invaluable when beginning our home-going VAD education program. These institutions were willing to share their experiences, written education, lecture materials, discharge binders, and discharge checklists. Resources were also provided by the manufacturer of the durable VAD device, including brochures, patient resources, reimbursement tools, and educational videos. The first step was to assemble a multidisciplinary team, including heart failure physicians, cardiovascular surgeon, perfusionist, pharmacist, mechanical circulatory support team members, nurses, occupational therapists, and physical therapists. This dedicated group was responsible for the educational content and program oversight. Educational responsibilities were based on the individual team members' expertise. For example, mechanical support team members and perfusionists were responsible for the VAD hands-on education and training, whereas the pharmacist, heart failure physicians, and nursing staff were responsible for medication education. The heart failure physicians were responsible for training the outreach community. The next step was to identify patients eligible for discharge. Patient and family factors identified as important included 1) stable medication regimen, including diuretics, anticoagulation, and blood pressure medications; 2) optimized nutritional support; 3) appropriate family support; and 4) ability to complete a comprehensive VAD education program. The next step was to develop the VAD education program for the patient, family, and community.

EDUCATION PLAN

Patient and Family Training

Didactic lectures included topics such as indication for VAD implantation, surgical procedure, post-operative care and management, anticipated hospital course, stroke education, follow-up care, education plan, anticoagulation therapy, and expectations for continued therapy in the home setting. Before implant, the pump and controller are introduced with a hands-on demonstration and discussion of the detailed education plan. After implant, age-appropriate information is provided to patients and caregivers via educational sessions limited to 30 minutes to avoid

overwhelming the learner. These sessions used didactic lectures, written handouts and hands-on demonstration. Introduction to each topic was performed by appropriate individual from the multidisciplinary VAD team. Ongoing daily education reinforcement was the responsibility of each member of the mechanical circulatory support team. All education was documented in a log kept at the bedside. Each training session focused on a single topic including introduction to the controller face, battery use and care, power exchanges, review of alarms, troubleshooting, and emergencies. To assess mastery of each topic, a written quiz (Figure 1) was administered before moving on to the next topic. Patient and caregiver ability to complete tasks was demonstrated through the use of written quizzes and multiple return demonstrations of the skills required. Integration of occupational therapists to supplement the hands-on portion of the training, including manual performance of power source changes, is sometimes necessary. Dressing changes are demonstrated during hands-on training, with written instructions provided for continued reference and review. Didactic topics include instructions for shower bag use, maintenance and care of driveline, dressing changes, and infection control. Dressing change supplies used at home are ordered to gain familiarity with the products that will be used at home. The patient and family complete a final hands-on high-fidelity simulation session using a mannequin, pump, controller, mobile power unit, and battery charger. The simulation session is used to assess mastery of skills and knowledge including alarms, troubleshooting, and emergency responses. Scenarios including battery failure, power failure, controller change out, driveline change out, and cardiovascular emergencies are covered during the final simulation session. A final written test is administered, including topics such as routine daily care, signs and symptoms of stroke, power sources, equipment maintenance, dressing care, and battery charger. The family and local providers are provided with a direct line to speak directly with a VAD-trained physician 24/7. Alternate contacts were provided for non-VAD-related medical questions, such as medication refills. The importance of adherence to medications and compliance with outpatient laboratory schedule as well as fluid management and nutritional status is also included. The caregivers are required to attend a cardiopulmonary resuscitation class approved by the American Heart Association provided by the institution before discharge.

Field Trip

On completion of VAD training, the family participates in a half-day field trip within the hospital campus unaccompanied by hospital staff. This trip fosters confidence and independence while having a safety net of medical staff readily available. After a successful on-campus field trip, the patient and caregivers go on a full-day, off-campus field

HeartMate 3 Driveline Dressing Quiz

1. How often should you change driveline dressing? _____
2. How many times should you clean the driveline exit site? _____
3. What keeps your driveline in place to prevent tugs? _____
4. What do you use to clean driveline cable? _____
5. What should you clean first?
 - a. Work surface
 - b. Hands
 - c. Driveline site
6. Which do you use to remove the old dressing?
 - a. Sterile gloves
 - b. Clean Gloves
 - c. Clean Hands
7. When should you call your VAD Team?
 - a. Redness
 - b. Drainage
 - c. Odor
 - d. All of the Above

Figure 1. Sample of written quiz used to assess mastery of a given topic.

trip. Examples of off-campus field trips include the zoo, movie, mall, or museum. This outing is aimed at increasing confidence in independently performing activities of daily living with a VAD.

Community Education

Local community education includes anyone who may interact with the patient outside the hospital: physical/occupational therapists, home health nurses, school personnel, emergency medical services personnel, medical transport team members, primary care physician and staff, and emergency department staff. Education for each group is tailored to meet their specific needs: emergent contact information for 24/7 support from the VAD team, troubleshooting and changing power source if deemed necessary, basic resuscitation highlighting the nuances of a patient with a VAD, i.e., no palpable pulse, and a step-by-step plan for transport to the tertiary care facility. This educational program for the local community included multidisciplinary lectures given by the heart failure physician through computer-based didactic and hands-on demonstration of device. Rapid reference sheets, including contact information, alarms and troubleshooting, and list of supplies, are provided to family and all

community partners. The power company is notified by phone and formal letter stating the use of life sustaining medical equipment and the urgency to restore power to the residence in the event of power outage. Patient and family are educated on the need for a home generator and are instructed to go to a local hospital or EMS department in the event of prolonged power outage.

Discharge

Once the education plan for the patient, family, and community is complete, the discharge checklist (Figure 2) and home safety checklist (Figure 3) are reviewed to assess readiness for discharge. A discharge binder is assembled, which includes emergency contact numbers, quick reference sheet for troubleshooting/alarms, daily log sheets (Figure 4), dressing change instructions, copies of all education modules and quizzes, emergency preparedness checklist, medication and outpatient laboratory testing information, and schedule for equipment maintenance. The emergency preparedness checklist for non-medical emergencies includes fully charged batteries, 1 week supply of medications, electric company phone number for extended power outages, working flashlight, and alternate locations with backup power generators

HeartMate Discharge Checklist				
Patient Name:			DOB:	
Skills Checklist				
Skill	Patient Date/Initials	Caregiver 1 Date/Initials	Caregiver 2 Date/Initials	Competent (skill leader)
Battery Teaching				
Controller Teaching				
Dressing Teaching				
Alarms Teaching/ Simulation				
Final Quizzes				
In-Hospital Trip				
Out of Hospital Trip				
VAD Team				
Task	Date	Signature		
Demonstrate Emergency Call				
Document emergency preparedness information				
Follow up appt with HF				
Electric Company communication				
Coumadin Nurse Education				
CPR Training				
EMS Training				
School Training				
Med Alert Bracelet				
All Items Labeled				
Task	Date	Signature		
Backup Controller Charged				
Component Replacement Schedule				
Medications dispensed				
Nitrile gloves				
Alcohol swabs				

Figure 2. Discharge checklist.

such as local fire department or hospital. All VAD-related equipment is labeled with phone numbers for the VAD team which is available 24/7. Business cards are provided stating the necessity of life-sustaining equipment for use at airports and security checkpoints. These cards specify that the batteries and controller cannot be removed from the patient and a manual security inspection is requested. A medical identification bracelet is supplied to the patient stating the presence of a VAD, the lack of a palpable pulse, and directions to call 911 and the VAD physician directly.

Follow-up

After discharge, there are clinic visits weekly for 4–6 weeks. During each visit, the patient must bring their log sheet documenting daily settings, daily controller self-test, date/time of dressing change, photo of driveline site, weight, and recent international normalized ratio/anticoagulation changes. Event history is downloaded during this visit and reviewed. Time between clinic visits is lengthened as appropriate for the individual patient and family.

HeartMate Home Safety Checklist				
Patient Name:			DOB:	
Miscellaneous				
	Yes	No	Action needed	Action Taken/ Date Completed
Is your home free of clutter and dangerous objects?				
Free of potentially dangerous environments (open water, swimming pools, ponds, fountains, etc)				
Rugs, mats or runners have slip resistant backing? All carpets and runners secure?				
Adequate telephone for emergency communication?				
Do you have all necessary emergency numbers posted and readily available?				
Electric				
Are you up to date on your electric payments?				
Is the home electrically safe, with enough safe, grounded and working outlets? (at least one outlet must be dedicated to powering the power module) Note: no extension cords allowed				
Halls and Stairs				
Do you have stairs in your home? If so, how many?				
Are stairs in good condition? Have nonskid surfaces?				
Halls and Stairs (continued)				
Is there a bedroom on the first floor?				
Do the stairs have sturdy, easy-to-grip railings, at least waist height?				
Are the hallways and stairs are adequately lit?				
Bathroom				
Is there a bathroom on the first floor? If so, does the bathroom have a shower?				
Do you have a grab bar on the wall or side of the shower (properly installed and designed to hold the weight of a person)?				
Do you have a shower chair available to you?				
Please note that before discharge, we will need to notify your electric company that you are dependent upon electricity- We will need your account number in order to do so. _____(please initial) Patient or designated family member responsible for completion of this form: (By signing below, you are agreeing to get ALL the above safety hazards corrected before discharge home). VAD Team Signature: _____ Print Name: _____ Signature _____ Date: _____ Time: _____				

Figure 3. Home safety checklist.

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