



Care of Patients with Heart Failure

How self-care education in ventricular assist device programs is organized and provided: A national study

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ABSTRACT

Objective: To describe the care delivery structure and elements used for patient self-care education in ventricular assist device (VAD) programs.

Background: Use of VADs as destination therapy and to sustain organ function until cardiac transplantation has increased 517% since 2007. Elements of VAD-specific self-care education have not been described.

Methods: A 26-item survey measuring VAD self-care education resource use, organizational, employment, behavioral and labor variables was sent to VAD coordinators at all US VAD centers ($N = 111$) in 2011. Two subsequent mailings yielded a 63% ($n = 71$) return rate. Analysis included descriptive statistics and cluster analysis.

Results: Element use varied across programs. Reliance on single educational and evaluation methods, and lack of return demonstration were noted. VAD coordinators reported extensive caregiver, hospital provider, and community educational responsibilities in addition to patient self-care education.

Conclusions: VAD self-care education programs varied by hospital. Future research is needed to determine if specific care delivery structures or elements used in self-care education improve VAD patient outcomes.

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Introduction

Approximately 6 million Americans live with heart failure (HF).¹ More than 670,000 patients are diagnosed with heart failure annually.¹ Last year, approximately 2800 Americans with HF awaited a life-saving heart transplant, but less than 1900 donor hearts were available.² Patients with advanced HF who are not transplanted immediately must rely on alternative means of survival, one of which is ventricular assist device (VAD) placement. In addition, HF patients who do not meet cardiac transplantation criteria may receive a VAD as destination therapy, or DT.³ In the United States, VAD implantation for either reason has grown from 280 implants per year in 2007 to 1450 implants in 2011.⁴ As a result, more than 5500 Americans are living with VADs and many more are expected given the aging of the baby boomer generation.⁴

Much is unknown about how hospital programs are designed to prepare patients and their lay caregivers to perform self-care activities after VAD implantation. Although the emotional and physical impact of VAD therapy and quality of life has been described,^{5,6} three aspects of patient self-care have not been

explored: methods used to educate patients and lay caregivers in performing VAD self-care, resources used to support learning self-care skills, and evaluation of patient and caregiver self-care proficiency.^{5,6} Patients with VADs must perform self-care actions such as wound care at the VAD exit site, immobilization of the VAD exit site (to promote healing), exchange of power sources from battery to power-base unit (PBU) and, daily diagnostic self-testing.⁷ Evaluation of the VAD alarm recognition system, adherence to safety precautions and performance of emergency interventions are also required.^{7,8} Self-care education as a treatment must be described before evaluating how specific hospital care delivery structures and elements of self-care education influence outcomes such as mortality, infection, quality of life, device malfunction, patient satisfaction, and symptom management.

In chronic illness, the patients' participation in self-care is often a necessity rather than a choice.^{9,10} VAD self-care requisites are demanding and time-intensive.^{6,7} Daily maintenance and monitoring of the VAD requires psychomotor and cognitive skills for proper device functioning and to allow for satisfying levels of independence in activities of daily living. Self-care demands may seem overwhelming to the VAD patient and lay caregiver. Psychosocial burden relative to self-care after VAD implantation may manifest itself as feelings of uncertainty and anxiety.⁵ Patients

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reported relief after returning home, but adapting to daily life with the VAD was difficult.^{5,7} Continuing to apply self-care knowledge and skills was stressful for patients and lay caregivers, because neither felt proficient or confident in their abilities.^{5,7}

Device manufacturer recommendations define VAD educational content standards but there are no evidence-based recommendations that suggest who should provide education, how and how often providers should offer education, and when and how providers should evaluate patient and lay caregiver competency. The role of nurses as VAD coordinators has been examined, but there is limited information regarding the coordinator role in patient and lay caregiver education prior to hospital discharge.¹¹ Education is traditionally a nursing role, making the identification of care delivery structures and elements of VAD self-care education an important nursing practice topic.¹² Understanding how and to what degree VAD programs are preparing patients and their lay caregivers for self-care could provide a means to evaluate self-care training methods across hospitals, and it may offer insight into the self-care training of individuals with other chronic diseases who must rely on life-sustaining devices. The purpose of this study was to describe VAD program structures and elements of self-care education utilized by U.S. hospitals during the initial postoperative phase. In this study, VAD program care delivery structures were defined as organizational facets such as reporting structures (reporting was defined as accountability to a Department Chair for service, patient and/or fiscal concerns), provider roles and responsibilities, and required staff preparation. Education elements were defined as provider labor, education materials, timing and duration of educational sessions delivered to patients and lay caregivers, methods used for validation of patient and lay caregiver skill performance, and post-discharge support available to the patient and lay caregiver.

Methods

We used a descriptive cross-sectional design. Institutional Review Board (IRB) approval was secured prior to beginning recruitment. The Minnick and Roberts Outcome Model (Fig. 1)¹³ was used to organize variable factors, and variables were measured via a 26-item survey. The Minnick and Roberts Outcome Model aided identification of variables under the control of clinical administrators which could influence care delivery structures and elements of self-care education. Survey content evolved from a review of the

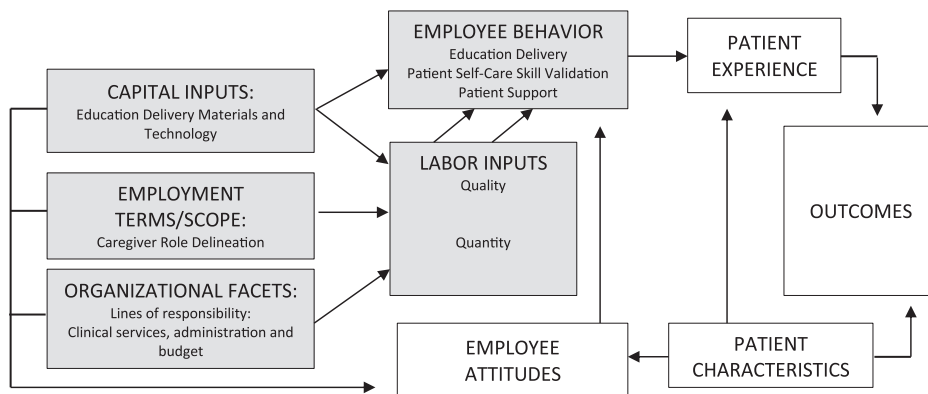
literature^{11,12} and the PI's clinical experience. Table 1 lists variables included in the survey. Variables described VAD program reporting structures, provider role delineation and role components, self-care teaching methods used, educational resources and validation methods, and hospital-provided patient and lay caregiver support resources following discharge. Face and content validity were supported by an independent card sort method.¹⁴ Two independent registered nurse (RN) sorters, one RN was a national expert in health services research, assigned each item to a concept category within the Minnick and Roberts framework with >91% agreement. Three APNs and one RN experienced in the care of VAD patients completed a pilot survey and wording revisions were made. An electronic version of the survey was pilot-tested for technological accuracy. The survey used a structured question format, with dichotomous response and Likert scale items.

Setting and sample

All U.S. hospitals that provided VAD services in 2011 were surveyed. VAD programs were identified by comparing listings from the Center for Medicare and Medicaid Services (CMS), the Inter-agency Registry for Mechanically Assisted Circulatory Support (INTERMACS), and clinician membership in the International Consortium of Circulatory Assist Clinicians (ICCAC).^{4,15,16} INTERMACS is a publicly accessible, federally funded registry of clinical and demographic data of VAD patients and ICCAC membership included VAD coordinators from more than 90 U.S. hospitals.⁴ After excluding pediatric hospitals, hospitals with inactive programs, and duplicates from the three source documents, 111 of 124 hospitals remained. VAD program mailing addresses from the ICCAC membership roster or hospital websites were obtained. The survey was addressed to VAD program coordinators, because this group has an in-depth knowledge of VAD care elements along the continuum of care.

Data collection

Prior to mailing surveys, we announced the study on an Internet virtual bulletin board used by VAD coordinators. A cover letter included information regarding risks and benefits of participation, assurance of confidentiality, and instructions for accessing an on-line version of the survey. All messages sent to VAD coordinators



Note: Shaded areas indicate variable categories included in the study.

Fig. 1. The Minnick and Roberts Outcome Model. Shaded areas indicate variable categories included in the study. Taken from Outcome Assessment in Advanced Practice Nursing, 2nd Edition, Kleinpell, Springer Publishing Company, LLC, 2009.

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