ENABLE-LVAD: Improving the LVAD Caregiving Experience Through Clinician Training



Jamie Pfahl, BA¹; Jocelyn S. Thompson, MA^{1,2}; Daniel D. Matlock, MD, MPH^{1,2}; Larry A. Allen, MD, MHS^{1,2};

J. Nicholas Dionne-Odom, PhD, RN,3,4,5; Marie A. Bakitas, DNSc, CRNP3,4,5; Colleen K. McIlvennan, PhD, DNP, ANP1,2

Background

- Unpaid family caregivers (FCGs) of patients with left ventricular assist devices (LVADs) experience significant emotional strain in the months following LVAD implantation.
- There are currently no formalized resources or training materials for clinicians to reduce caregiver strain.
- The evidence-based ENABLE (Educate, Nurture, Advise Before Life Ends) intervention for palliative care coaching and caregiver support has previously been used and studied with cancer and heart failure patients.
- **ENABLE-LVAD** aims to improve the LVAD caregiving experience through clinician and caregiver education and support, by adapting the ENABLE intervention to the LVAD setting.

ENABLE-LVAD modules include:

1. How to Handle Problems

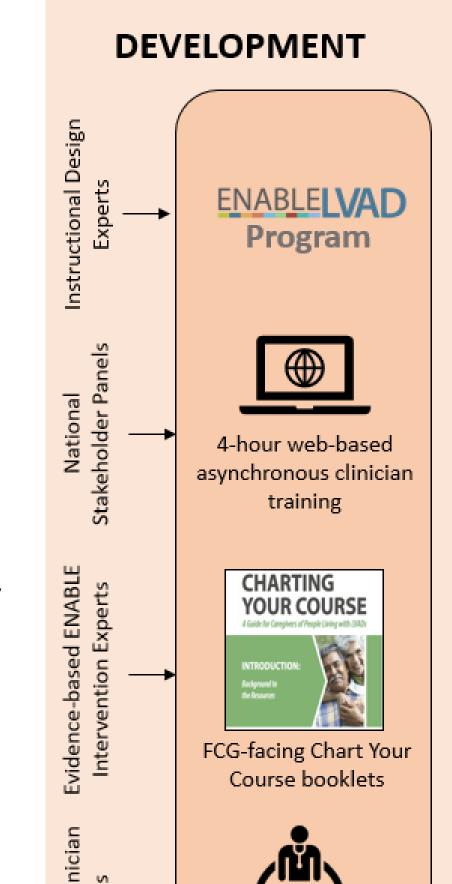
3. Being a Partner in Symptom

4. Talking About What Matters

Most and Making Choices

2. Taking Care of You

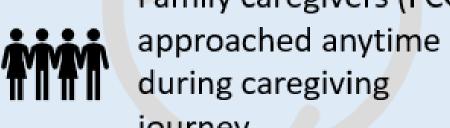
Management



Methods

DELIVERY

Certified Caregiver Coach Family caregivers (FCGs)



journey (added benefit when approached around time of implant, periods of stress)

Delivery is flexible to meet the needs of FCG and clinician (virtual, phone, or in-person)

- One-on-one (gold standard)
- Support group setting
- Modules completed in isolation or out of order
- FCGs using CYC booklets independently

DISSEMINATION



Social media engagement engagement



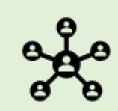


Mailed free promotional boxes to LVAD programs



National webinars

Networking at professional society meetings



- Subject matter experts and instructional design team created ENABLE-LVAD materials: (1) self-paced online CME-eligible clinician training and (2) FCG-facing Charting Your Course (CYC) guidebooks: https://patientdecisionaid.org/enable-lvad
- 6-month post-registration survey assessed: (1) training completed (Adoption), (2) ENABLE-LVAD use in practice (Implementation), (3) volume of FCGs reached (Reach), (4) intention for continued use (Maintenance), and (5) training and intervention feedback.

Results

- 174 clinicians registered for the training and 40 (23.0%) completed all modules.
- Of those who completed the training, all reported that it was useful.
- 153 registrants have been sent the 6month survey with 42 completing it (27.5% response rate).
- Of those who completed the training and responded to the survey (n=29, 72.5% response rate), over one-third (n=10, 34.5%) used ENABLE-LVAD with FCGs, and 100% of those planned to continue using it.
- Among training completers who are not yet using ENABLE-LVAD with FCGs (n=19), 68.4% (n=13) reported considering or planning to use it in the future.
- "I think the concepts, techniques, and philosophy behind the course is brilliant."
- "I plan to use this information to help caregivers better navigate shared decision making, understand heart failure, and navigate the complex caregiving role. This course will equip me to better support caregivers as they go through this process."



Conclusions

- ENABLE-LVAD training helps fill a crucial need for resources and support to address LVAD caregiver burnout and fill a gap in clinician knowledge and skills around complex caregiving discussions
- The flexibility of an interactive, selfpaced online training model is important to maximize adoptability and implementation.
- This model is readily translatable to other chronic conditions by modifying the disease-specific information on prognosis and symptom management.
- Challenges of this model are clinicians' lack of time and the lack of incentives to use these resources and strategies
- Future work should address these barriers by targeting health policy related to FCGs—such as financial incentives to include them as part of the care team--and evaluating the effectiveness of this training on outcomes with FCGs.

Disclosures

This project was funded as a PCORI implementation project "Expanding a Shared Decision Making Program for Patients Considering LVAD Treatment", HSRP20191566.

¹University of Colorado, School of Medicine, Aurora, Colorado; ²Adult and Child Consortium for Outcomes Research and Delivery Science, Aurora; Colorado; ³School of Nursing, University of Alabama at Birmingham, Birmingham, Alabama; ⁴Division of Gerontology, Geriatrics, and Palliative Care, School of Medicine, University of Alabama at Birmingham, Alabama; ⁵Center for Palliative and Supportive Care, University of Alabama at Birmingham, Alabama