

Project ENABLE (Educate, Nurture, Advise Before Life Ends)

Summary

- **Need:** To enhance palliative care access to rural patients with advanced cancer and their family caregivers.
- **Intervention:** Project ENABLE consists of: 1) an initial in-person palliative care consultation with a specialty-trained provider and 2) a semi-structured series of weekly, phone-delivered, nurse-led coaching sessions designed to help patients and their caregivers enhance their problem-solving, symptom management, and coping skills.
- **Results:** Patients and caregivers report lower rates of depression and burden along with higher quality of life.

Evidence-level

Evidence-Based ([About evidence-level criteria](#))

Description



Palliative care is often limited in resource-scarce rural communities. While palliative care has traditionally been offered only after exhausting curative treatment options, a growing number of clinical trials demonstrate that offering [palliative care at the time of diagnosis and concurrent with disease-oriented care](#) can help improve patients' symptoms, quality of life, and mood and help them and their caregivers plan for an unpredictable future.

Project ENABLE (Educate, Nurture, Advise, Before Life Ends) is a telehealth approach that provides palliative care to patients with serious illnesses and their family caregivers. ENABLE was developed in rural New Hampshire and Vermont and is now being implemented and tested in the southeastern United States and in selected areas of Honduras, Turkey, and Singapore.

History of Project ENABLE:

Project ENABLE I (1998-2001) was developed through a Robert Wood Johnson Foundation-funded demonstration project involving 380 patients at three northern New Hampshire cancer practices: the [Norris Cotton Cancer Center](#) (NCCC) at Dartmouth-Hitchcock Medical Center in rural Lebanon, Oncology Associates in Manchester, and a Critical Access Hospital in rural

Berlin. The goals were to provide a supportive care intervention to patients who were newly diagnosed with advanced cancer and had limited access to palliative care.

A nurse coach met with patients to facilitate a 4-session seminar guided by the [Charting Your Course](#) guidebook, which helps patients and families better cope with their physical, functional, spiritual, and functional needs. The nurse coach also coordinated care between the cancer centers and their communities. Family caregivers were invited but not required to attend. If they were interested but unable to attend in person, nurse coaches provided the content to patients and families via phone.

ENABLE II (2003-2008) was a randomized controlled trial (RCT) funded by the [National Cancer Institute](#) (NCI). Building on ENABLE I, including adapting the in-person intervention to one delivered by phone, the study's aim was to evaluate the efficacy of ENABLE to improve quality of life, symptoms, and mood for patients with advanced cancer compared to standard care. Over 300 patients enrolled over 4 years: Half of the patients received ENABLE and half received usual cancer care. Family caregivers did not receive a specific intervention but were invited to participate in patients' in-person palliative care consultations.

ENABLE III (2010-2013), funded by the [National Institute of Nursing Research](#) (NINR), was an RCT examining the timing of providing the ENABLE early palliative care telehealth approach to patients and a parallel intervention for family caregivers. Patients and their caregivers were randomly assigned to receive the intervention immediately or 12 weeks after enrollment. The intervention included an in-person comprehensive assessment by a palliative care certified clinician followed by nurse coach-delivered telehealth sessions. (Patients received 6 sessions and caregivers received 3 sessions.) The patient and caregiver each had a different nurse so that each participant could share questions or concerns freely. Nurses maintained monthly contact with patients and caregivers after the sessions were completed.

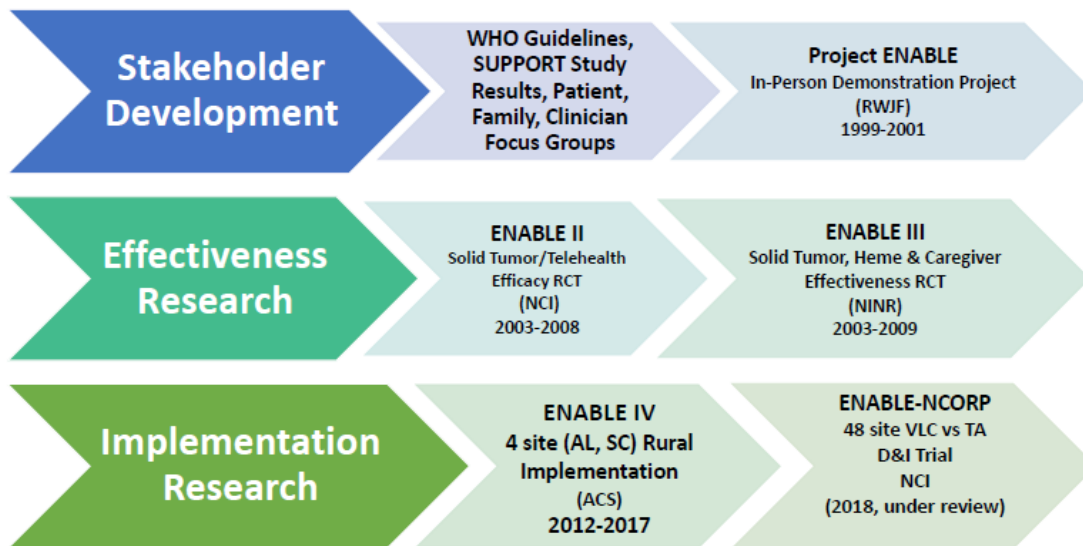
ENABLE IV (2012-2017), funded by the American Cancer Society, was an implementation science study using a virtual learning collaborative approach to implement ENABLE at racially diverse, rural-serving community cancer centers in Alabama and South Carolina. ENABLE implementation teams at each site were supported by the University of Alabama at Birmingham Coordinating Center experts via monthly videoconferences and annual site visits. Site teams reported monthly progress, patient experience, implementation costs, and lessons learned.

ENABLE CHF-PC (Comprehensive Heartcare for Patients and Caregivers: 2010-present), funded by Dartmouth SYNERGY and the National Palliative Care Research Center Pilot awards, adapted the early palliative care approach for cancer to also serve patients with heart failure and their family caregivers. A full-scale efficacy RCT is enrolling patients and caregiver participants across the Deep South. ENABLE: CHF-PC combines an in-person palliative consultation by a palliative care specialist and weekly nurse coach telehealth sessions (6 for patients and 4 for caregivers) and monthly follow-up. The sessions also follow “Charting Your Course” and services are tailored to meet a patient’s and family’s unique needs.

Current efforts are focusing on tailoring this early palliative care approach further for cancer family caregivers (ENABLE-CORNERSTONE) and for patients with chronic obstructive pulmonary disease (COPD) and family caregivers (early palliative care for COPD-EPIC).

Early Palliative Care ENABLE Trials (Cancer)

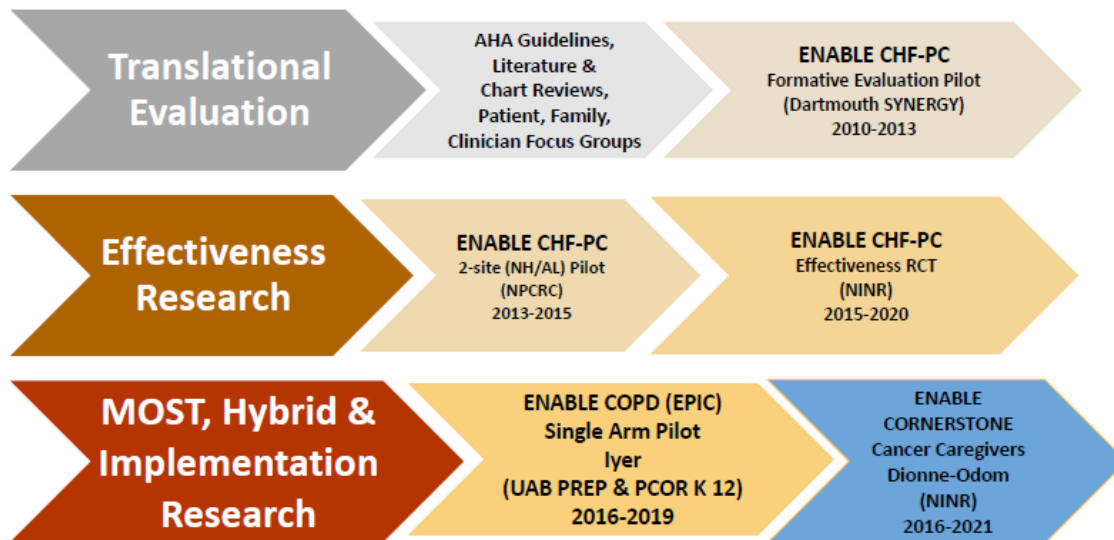
From Stakeholder Need to Effectiveness & Implementation Research



Early Palliative Care ENABLE Trials (Non-Cancer)

From Translation & Formative Evaluation to Effectiveness & Implementation Research

From Translation & Formative Evaluation to Effectiveness & Implementation Research



Services offered

Nurse coaches provide Charting Your Course sessions for patients and caregivers. These sessions cover topics such as symptom management, self-care, decision-making, and advance

care planning. While palliative care services are considered standardized, they can be tailored to meet the individual patient's and caregiver's needs.



Results

ENABLE I:

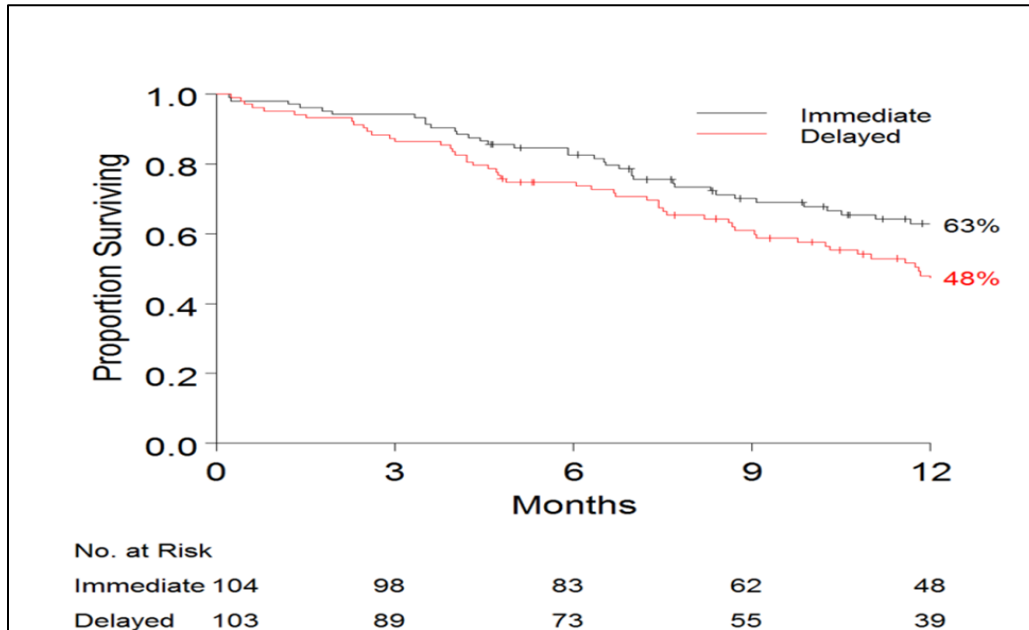
- Compared to national and regional data, a larger number of participants in ENABLE died in their preferred site. (For many participants, this meant dying in their own home.)
- A higher percentage of ENABLE family members reported that the patient and providers worked to ensure that patient preferences for medical treatment were followed.

ENABLE II:

- Intervention patients reported lower depressed mood and higher quality of life with trends towards improved symptom management and survival.
- ENABLE was listed as a [Research-Tested Intervention Program](#) (RTIP) by the National Cancer Institute.

ENABLE III:

- [Kaplan-Meier survival rates](#) one year after enrollment were 63% for those in the early intervention group, compared to 48% for those who began intervention 3 months later.
- Caregivers in the early intervention group had lower depression and stress burden scores.
- The American Society for Clinical Oncology (ASCO) identified ENABLE as one of the year's greatest advances in clinical cancer care.



ENABLE IV:

- Program coordinators developed and tested the ENABLE Implementation Toolkit to assess pre- and post-implementation success.
- They demonstrated feasibility of using a virtual learning collaborative (VLC) strategy to implement ENABLE in non-academic, community-based cancer practices that serve a high proportion of rural, minority cancer patients and their family caregivers.

ENABLE CHF-PC:

- Results of a pilot study demonstrated feasibility of carrying out ENABLE in New York Heart Association (NYHA) Class III/IV patients (n=61) and caregivers (n=48) at sites in New England and the Southeast U.S.
- Patients experienced moderate effect size improvements in QOL, symptoms, physical, and mental health; caregivers experienced moderate effect size improvements in QOL, depression, mental health, and burden. Small-to-moderate effect size improvements were noted in patients' hospital and ICU days and emergency visits.

For more information about Project ENABLE:

Bakitas, M., Dionne-Odom, J.N., Pamboukian, S., Tallaj, J., Kvale, E., Swetz, K., Azuero, A., Frost, J., Wells, R., Keebler, K., Akyar, I., Ejem, D., Steinhauer, K., Smith, T., Durant, R., and Kono, A. (2017). Engaging Patients and Families to Create a Feasible Clinical Trial Integrating Palliative and Heart Failure Care Results of the ENABLE CHF-PC Pilot Clinical Trial. *BMC Palliative Care*. *BMC Palliative Care*, 16(1), 45. doi:10.1186/s12904-017-0226-8

Zubkoff, L., Dionne-Odom, J. N., Pisu, M., Babu, D., Akyar, I., Smith, T. Bakitas, M. A. (2017). Developing a "toolkit" to measure implementation of concurrent palliative care in rural community cancer centers. *Palliat Support Care*, 1-13. doi:10.1017/s1478951517000323

Bakitas, M.A. (2017). On the Road Less Traveled: Journey of an Oncology Palliative Care Researcher. *Oncology Nursing Forum*, 44(1), 87-95. [Article Abstract](#)

Bakitas, M.A., Elk, R., Astin, M., Ceronsky, L., Clifford, K.N., Dionne-Odom, J.N., ... & Smith, T. (2015). [Systematic Review of Palliative Care in the Rural Setting](#). *Cancer Control*, 22(4), 450-464.

Bakitas, M.A., Tosteson, T.D., Li, Z., Lyons, K.D., Hull, J.G., Li, Z., ... & Ahles, T.A. (2015). [Early Versus Delayed Initiation of Concurrent Palliative Oncology Care: Patient Outcomes in the ENABLE III Randomized Controlled Trial](#). *Journal of Clinical Oncology*, 33(13), 1438-1445.

Dionne-Odom, J.N., Azuero, A., Lyons, K.D., Hull, J.G., Tosteson, T., Li, Z., ... & Bakitas, M.A. (2015). [Benefits of Early Versus Delayed Palliative Care to Informal Family Caregivers of Patients with Advanced Cancer: Outcomes from the ENABLE III Randomized Controlled Trial](#). *Journal of Clinical Oncology*, 33(13). 1446-1452.

Dionne-Odom, J.N., Kono, A., Frost, J., Jackson, L., Ellis, D., Ahmed, A., ... & Bakitas, M. (2014). [Translating and Testing the ENABLE: CHF-PC Concurrent Palliative Care Model for Older Adults with Heart Failure and Their Family Caregivers](#). *Journal of Palliative Medicine*, 17(9), 995-1004.

Bakitas, M., Lyons, K.D., Hegel, M.T., & Ahles, T. (2013). Oncologists' Perspectives on Concurrent Palliative Care in a National Cancer Institute-Designated Comprehensive Cancer Center. *Palliative & Supportive Care*, 11(5), 415-423. [Article Abstract](#)

Maloney, C., Lyons, K., Li, Z., Hegel, M., Ahles, T.A., & Bakitas, M. (2012). [Patient Perspectives on Participation in the ENABLE II Randomized Controlled Trial of a Concurrent Oncology Palliative Care Intervention: Benefits and Burdens](#). *Palliative Care*, 27(4), 375-383.

O'Hara, R.E., Hull, J.G., Lyons, K.D., Bakitas, M., Hegel, M.T., Li, Z., & Ahles, T.A. (2010). [Impact on Caregiver Burden of a Patient-Focused Palliative Care Intervention for Patients with Advanced Cancer](#). *Palliative & Supportive Care*, 8(4), 395-404.

Bakitas, M.A., Lyons, K., Hegel, M., Balan, S., Brokaw, F., Byock, I., ... & Ahles, T. (2009). [Effects of a Palliative Care Intervention on Clinical Outcomes in Patients with Advanced Cancer: The Project ENABLE II Randomized Controlled Trial](#). *Journal of the American Medical Association*, 302(7), 741-749.

Bakitas, M., Stevens, M., Ahles, T.A., Kirn, M., Skalla, K., Kane, N., & Greenberg, E.R. (for Project ENABLE staff). (2004). Project ENABLE: A Palliative Care Demonstration Project for Advanced Cancer Patients in 3 Settings: One Project of the Robert Wood Johnson Foundation's "Promoting Excellence in End-of-Life Care." *Journal of Palliative Medicine*, 7(2), 363-372. [Article Abstract](#)

[FOR COMPLETE BIBLIOGRAPHY SEE:](#)

<http://www.ncbi.nlm.nih.gov/sites/myncbi/marie.bakitas.2/bibliography/40763517/public/?sort=date&direction=ascending>

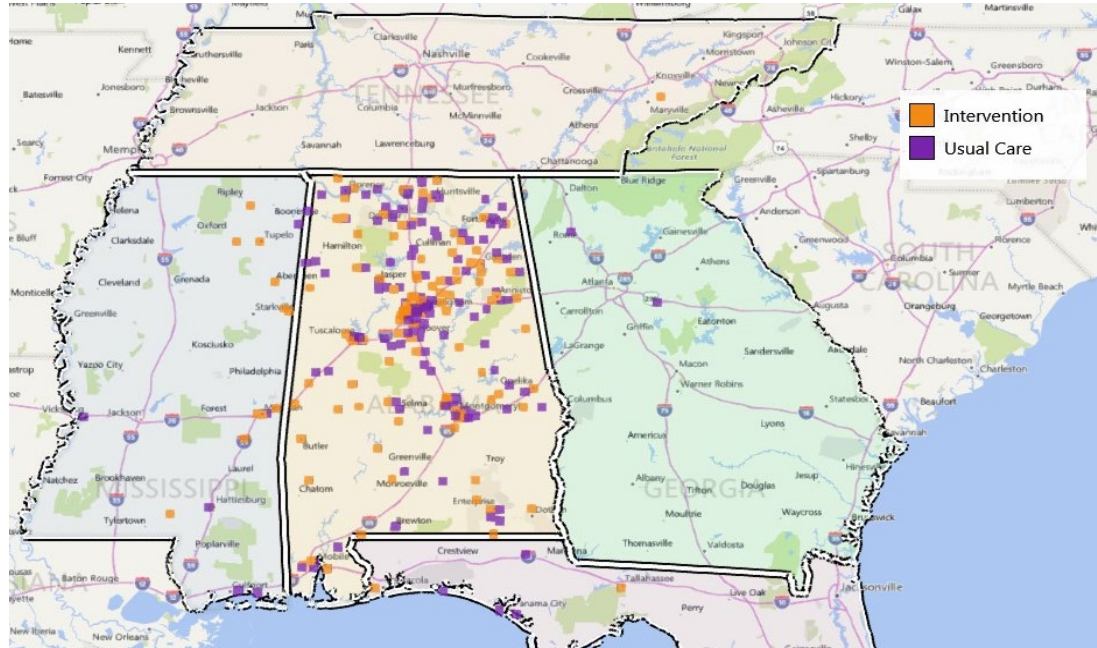


Figure: Locations of ENABLE CHF-PC trial participants

Barriers

Patient barriers include poverty and unemployment, level of education, mistrust of healthcare, travel to care and **lack of care model adaptation to community culture.**

Provider barriers include lack of palliative care education, experience, and expertise.

Policy/system barriers include inability of small cancer centers and practices to support palliative care expertise and **limited reimbursement available for palliative services.**

Replication

Implementation materials are available through RTIP and the authors' publications and presentations. Early lessons learned from the implementation study include:

- The importance of administrative and palliative care leadership buy-in, support, and commitment
- The need for oncologist champions
- Protected time for coaches to deliver the program
- The need for strategically incorporating ENABLE model elements into existing workflow patterns
- A referral trigger that does not rely solely on oncologist referral

Contact Information

Dr. Marie Bakitas, Professor and Marie L. O'Koren Endowed Chair / Associate Director
University of Alabama at Birmingham School of Nursing / UAB Center for Palliative and
Supportive Care

[UAB Center for Palliative and Supportive Care](#)

205.934.5277

mbakitas@uab.edu

Topics

Cancer

Cardiovascular disease

Hospice and palliative care

Informal caregivers

Telehealth

States served

National/Multi-State, Alabama, New Hampshire, Vermont