

IMPROVING PALLIATIVE CARE ACCESS THROUGH TELEHEALTH: THE ENABLE CLINICAL TRIALS



Marie Bakitas, DNSc, CRNP
J. Nicholas Dionne-Odom, PhD, RN
University of Alabama at Birmingham
Birmingham, AL

OBJECTIVES

Describe the evolution of the ENABLE intervention and clinical trials.

Identify the features of ENABLE that are particularly well-suited to rural patients and family caregivers.

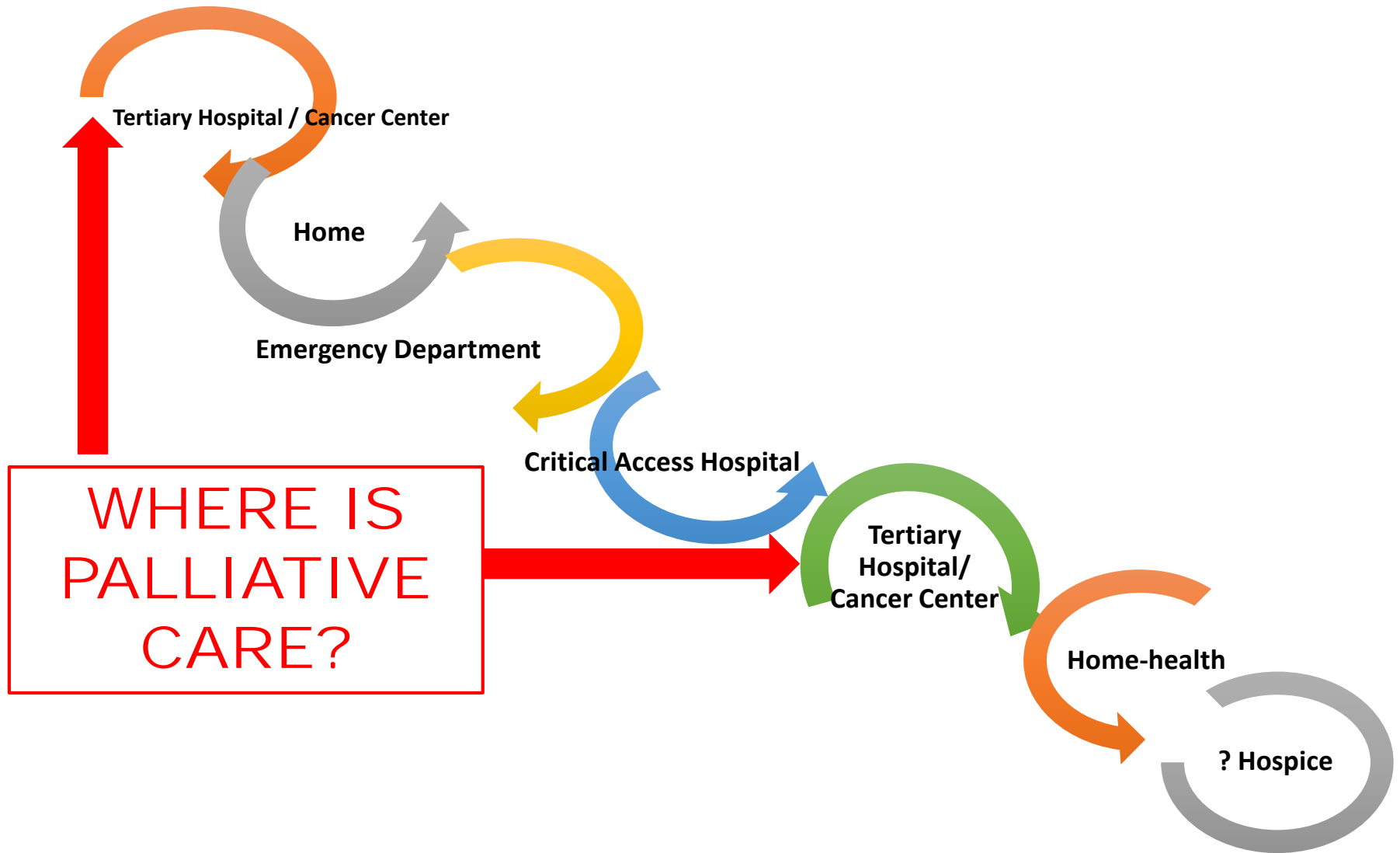
Propose future efforts that can improve palliative care for patients and family caregivers in rural environments.

PALLIATIVE CARE CHALLENGES IN PATIENTS WITH SERIOUS ILLNESS IN RURAL U.S.

- Maebel is 78 yo African American woman with recurrent breast cancer, lymphangic pulmonary metastases & dyspnea.
 - Admitted to local critical access hospital.
 - Baptist, 5 children, 10 grandchildren, 3 great-grandchildren all but 1 live 'up north'.
- She & family believe she will get better treatment at the academic center 90 miles away.
- Oncology recommends 'palliative' chemo; Maebel defers to MD advice.
- Family unable to visit due to transportation issues.
- Maebel gets short of breath, intubated, transferred to ICU.
- She dies alone following lengthy resuscitation effort while MDs attempt to contact family to understand her wishes for life-sustaining treatments.



Maebel's Transitional Journey



Project ENABLE

Educate, Murture, Advice, Before Life Ends



Goal: Determine a feasible model to introduce palliative/hospice principles at the time of new advanced cancer diagnosis (as recommended by the World Health Organization).

Funded by

The Robert Wood Johnson Foundation

Norris Cotton Cancer Center at Dartmouth Hitchcock Medical Center &

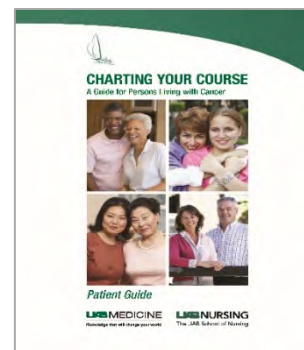
Visiting Nurse/Hospice of Vermont and New Hampshire



ENABLE Program

Educate, Nurture, Advice, Before Life Ends

- Newly-diagnosed advanced cancer patients & caregivers
- Multi-component psycho-educational telehealth
 - In person palliative care assessment
- ENABLE Phone coaching (Patient & Caregiver)
 - *Guided by Charting Your Course (CYC): An Intervention With Advanced Cancer and their Family Caregivers*



What is ENABLE?



Phone-based



Dyads
coached in
parallel



Advanced
practice nurse
coaches

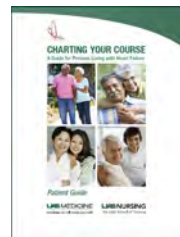


At
diagnosis

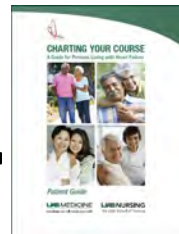
What ENABLE patients get...



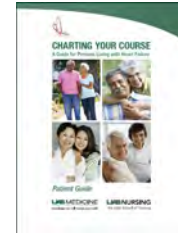
+



+



+



+

MONTH						
Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday

**In-person,
outpatient
palliative
care
consults**



Konda Keebler, MSN, RN
Nurse Coach



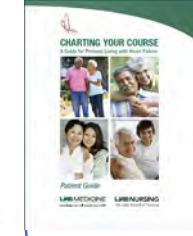
Elizabeth Sockwell, BSN, RN
Nurse Coach



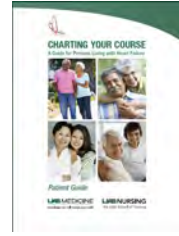
Rachel Walts, MSN, RN
Nurse Coach



Crystal Nwagwu, MSN, RN
Nurse Coach



+



+



**Charting Your Course
6 Sessions (30-60 min)**

**Monthly check-
in calls up to
48 weeks**

ENABLE
Session 1

What is your understanding of your illness?

- Palliative care is...
- [Importance of caregiver role]
- COPE attitude (McMillan, 2007)
- Problem solving support



Self-care and symptom management

Self-care (e.g. healthy eating, staying active)

Symptom management

Depression and Grief

Coping with loss

Spirituality

ENABLE
Session 2

ENABLE
Session
3

Communication/Decision-Making

Communication skills

Preparing for provider appointments

Support network

Medical decision-making

Decision aids (e.g. Ottawa)

Advance care planning

Charting Your Course

An Intervention for People
Living with Cancer

PATIENT GUIDE



Version 4/14/2011

Communication, Support and Decision-Making



Chapter 3

Distress Thermometer	50
Communicating with your Health Care Team	52
Asking for Help – Building a Support Network	53
Activity – Identifying a Support Team	54
Medical Decision-Making: Communicating About Your Choices for Care	56
• Tools That Help with Difficult Decision-Making	57
• Activity – Viewing the Shared Decision-Making Program® (DVD/Booklet)	57
“Looking Ahead: Choices for Medical Care When You’re Seriously Ill”	
• Activity - Ottawa Medical Decision-Making Guide	58
Ottawa Example: Should I Pursue Investigational Chemotherapy”	60
Advance Care Planning – An Important Medical Decision-Making Tool for ALL.....	61
Problem Solving Worksheet.....	63

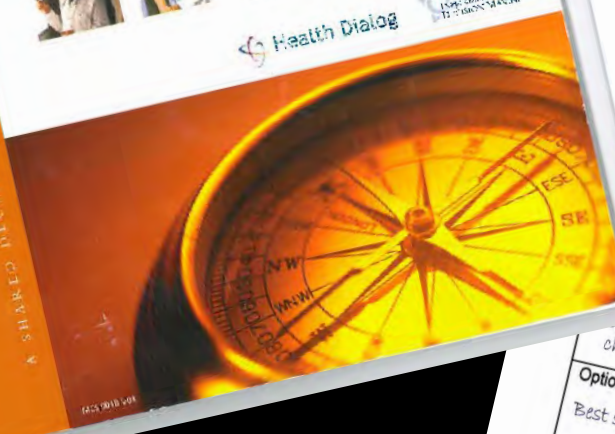
LOOKING AHEAD

Choices for medical care when you're seriously ill



Health Dialog

UNIVERSITY OF
TORONTO MEDICAL
FACULTY



A SHARED DECISION-MAKING PROGRAM

Ottawa Personal Decision Guide

Date: _____

Decision: What decision do you face? Should I pursue investigational chemotherapy?
 When do you need to make a choice? Next Monday
 How far along are you with making a choice?
 not thought about options thinking about options close to making a choice already made a choice

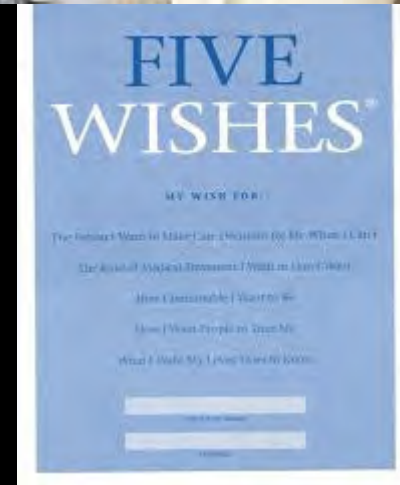
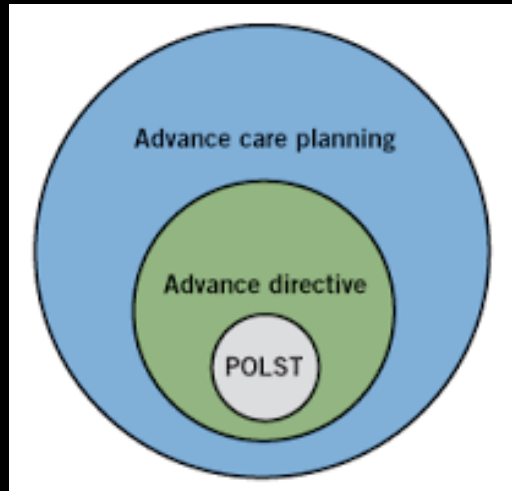
Certainty: Do you feel sure about the best choice for you?
 No Yes, which one?
 No Yes

Knowledge: Do you know which options are available to you?
 Do you know both the benefits and risks of each option?
 No Yes

Values: Are you clear about which benefits and risks matter most to you?
 A. In the balance scale below, list the options and main benefits and risks that you already know.
 B. Underline the benefits and risks that you think are most likely to happen.
 C. Use stars [★] to show how much each benefit / risk matters to you: 5 stars means it matters 'a lot'; No star means 'not at all'.

Option	Benefits (reasons to choose this option)		Risks (reasons to avoid this option)	
		How much it matters (★)		How much it matters (★)
Option 1 Best supportive care and investigational chemotherapy	Treatment might work better	5 ★	Unclear benefit	4 ★
	May help others later	2 ★	Unknown side effects	4 ★
Option 2 Best supportive care and standard chemotherapy	Breaking new ground	1 ★	At hospital longer	5 ★
	Benefit of treatment known	4 ★	??? of benefit not great	4 ★
Option 3 Best supportive care only	Side effects known	4 ★	Side effects	2 ★
	Less time at hospital	4 ★	Still at hospital	2 ★
	Almost no hospital time	3 ★	Could die sooner	5 ★
	Move home/family time	3 ★	More burden to family	5 ★
	Might feel better	3 ★	Family will be let down	4 ★

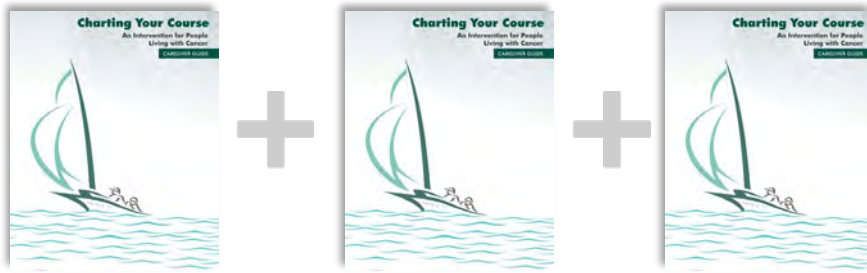
Advance Care Planning Coaching





ENABLE Sessions
4 Life Review
5 Forgiveness
6 Legacy
Outlook-Steinhauser et al.

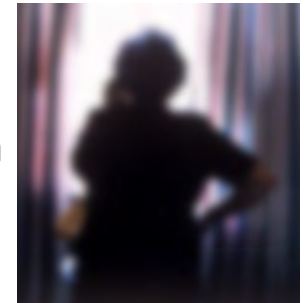
WHAT ENABLE CAREGIVERS GET...



**Charting Your Course
Sessions (30-60 min) X 3**

MONTH						
Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday

**Monthly
check-in
calls**



**Bereavement
call**

ENABLE
Caregiver
Session 1

Tell us about yourself?

Palliative care is...

Importance of caregiver role

COPE attitude (McMillan, 2007)

Problem solving support



Self-care and symptom management

Self-care (e.g. healthy eating, staying active)

Symptom management

Depression and Grief

Coping with loss

Spirituality

**ENABLE
Caregiver
Session 2**

Communication/Decision-Making

Communication skills

Preparing for provider appointments

Support network

Medical decision-making

Decision aids (e.g. Ottawa)

Advance care planning

ENABLE
Caregiver
Session 3

TAKE-HOME MESSAGE

Early group caregivers had:
↓ depressed mood ($p=.02$)
↓ stress burden ($p=.01$)
(*trend*) ↑ QOL ($p=.07$)

JOURNAL OF CLINICAL ONCOLOGY

ORIGINAL REPORT

Benefits of Early Versus Delayed Palliative Care to Informal Family Caregivers of Patients With Advanced Cancer: Outcomes From the ENABLE III Randomized Controlled Trial

J. Nicholas Dionne-Odom, Andres Azuero, Kathleen D. Lyons, Jay G. Hull, Tor Tosteson, Zhigang Li, Zhongze Li, Jennifer Frost, Konstantin H. Dragnev, Imatullah Akyar, Mark T. Hegel, and Marie A. Bakitas

See accompanying editorial doi: 10.1200/JCO.2014.60.5386 and article doi: 10.1200/JCO.2014.58.6362

A B S T R A C T

Purpose

To determine the effect of early versus delayed initiation of a palliative care intervention for family caregivers (CGs) of patients with advanced cancer.

Patients and Methods

Between October 2010 and March 2013, CGs of patients with advanced cancer were randomly assigned to receive three structured weekly telephone coaching sessions, monthly follow-up, and a bereavement call either early after enrollment or 3 months later. CGs of patients with advanced cancer were recruited from a National Cancer Institute cancer center, a Veterans Administration Medical Center, and two community outreach clinics. Outcomes were quality of life (QOL), depression, and burden (objective, stress, and demand).

J. Nicholas Dionne-Odom, Andres Azuero, Imatullah Akyar, and Marie A. Bakitas, University of Alabama at Birmingham, Birmingham, AL; Kathleen D. Lyons, Jay G. Hull, Zhigang Li, and Mark T. Hegel, Dartmouth College; Tor Tosteson and Zhongze Li, Norris Cotton Cancer Center, Hanover; and Jennifer Frost and Konstantin H. Dragnev, Dartmouth-Hitchcock Medical Center, Lebanon, NH.

Published online ahead of print at www.jco.org on March 23, 2015.

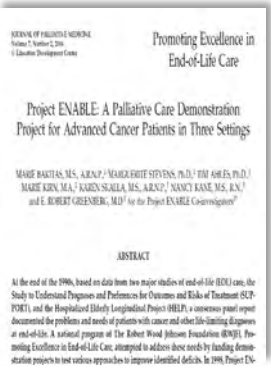
Supported by Grant No.

ASCO

CLINICAL
CANCER
ADVANCES
2016

ASCO's 11th Annual Report
on Progress Against Cancer

ENABLE is an Evidence-Based Early Palliative Care Intervention



- **ENABLE I (RWJ-funded demonstration project 1999-2001)**
 - primary feasibility data; led to the ENABLE II efficacy RCT
- **ENABLE II (N=322 patients, NCI R01 CA101704; 2003-2009)**
 - 4 sessions by palliative care APN + monthly follow-up vs. usual care
 - Outcomes: ↑QOL, mood; (symptom intensity & survival trends)
- **ENABLE III (N= 207 patients, 122 caregivers; 2010-2013)**
 - Early vs delayed intervention (3 months after diagnosis)
 - Early Intervention
 - ↑ patient survival by 15% (p=.003)
 - No difference in PROs
 - Early caregivers: ↑ mood & QOL, ↓ stress burden

JAMA
 FEDERAL COVERED TRANSACTION

Effects of a Palliative Care Intervention on Clinical Outcomes in Patients With Advanced Cancer
 The Project ENABLE II Randomized Controlled Trial

Marie Baugas, MS, Aranz; Kathleen Davis-Leman, MS, DVM; Scott T. DeGuz, PhD; Stefan Hahn, MD; Frances C. Braden, MS, RN; Joelle Saville, PhD; Jon C. Hull, PhD; Zhuang Li, MS; Terri H. Anderson, MS; Jo R. Brook, MD; Tim T. Ahles, PhD

Context: There are few randomized controlled trials on the effectiveness of palliative care interventions to improve the care of patients with advanced cancer.

Objective: To determine the effect of a nursing-led intervention on quality of life, symptom intensity, mood, and resource use in patients with advanced cancer.

Design, Setting, and Participants: Randomized controlled trial conducted from November 2003 through May 2008 of 322 patients with advanced cancer in a rural, National Cancer Institute-designated comprehensive cancer center in New Hampshire and affiliated outreach clinics and a VA medical center in Vermont.

Interventions: A multicomponent, psychoeducational intervention (Project ENABLE) (educational materials, before-the-need) conducted by advanced practice nurses consisting of a weekly educational session and monthly follow-up sessions until death or study completion (n=161) vs usual care (n=161).

Main Outcome Measures: Quality of life measured by the Functional Assessment of Cancer Therapy (FACT) and the Palliative Care Outcomes Scale (PCOS).

JOURNAL OF CLINICAL ONCOLOGY ORIGINAL REPORT

Early Versus Delayed Initiation of Concurrent Palliative Oncology Care: Patient Outcomes in the ENABLE III Randomized Controlled Trial

Marie A. Bailey, Terri H. Anderson, Frances C. Braden, Kathleen Davis-Leman, Scott T. DeGuz, Stefan Hahn, Jon C. Hull, Joelle Saville, Jo R. Brook, Tim T. Ahles

See accompanying editorial on: 10.1200/JCO.2014.01.0008 and article on: 10.1200/JCO.2014.01.0009

ABSTRACT

Background: Randomized controlled trials have supported integrated oncology and palliative care (PC) because optimal timing has not been evaluated. We investigated the effect of early versus delayed PC on quality of life (QOL), symptom impact, mood, time survival, and resource use.

Patients and Methods: Between October 2010 and March 2013, 207 patients with advanced cancer at a National Cancer Institute cancer center in Vermont (rural Medical Center) and community outreach sites were randomly assigned to receive an intensive PC intervention (n=103) or usual care (n=104). The intervention group was provided by an advanced practice nurse (APN) who worked with the oncologist at 1-month intervals. Usual care was provided by the oncologist. The primary end point was QOL, symptom impact, mood, time survival, and resource use. Secondary end points were caregiver mood, time survival, and health status.

Results: Overall patient-reported outcomes were not statistically significant after enrollment (QOL, P = .24; symptom impact, P = .08; mood, P = .09) or before death (QOL, P = .20; symptom impact, P = .20; mood, P = .65). Kaplan-Meier time survival rates were 52% in the early group and 48% in the usual care group (P = .100). Resource use was not significantly different between groups.



Patient perspectives on participation in the ENABLE II randomized controlled trial of a concurrent oncology palliative care intervention: Benefits and burdens

Palliative Medicine
0(0), 1–9
© The Author(s) 2012
Reprints and permission:
sagepub.com/journalsPermissions.nav
DOI: 10.1177/0269216312445188
pmj.sagepub.com

Cristine Maloney Department of Anesthesiology, Section of Palliative Medicine, Dartmouth-Hitchcock Medical Center, Lebanon, NH; Department of Internal Medicine, Gifford Medical Center, Randolph, VT, USA

Kathleen Doyle Lyons Department of Psychiatry, Dartmouth Medical School, Hanover, NH, USA

Zhongze Li Biostatistics Shared Resource, Norris Cotton Cancer Center, Dartmouth College, Hanover, NH, USA

Mark Hegel Department of Psychiatry, Dartmouth Medical School, Hanover, NH, USA

Tim A Ahles Department of Psychiatry, Memorial Sloan-Kettering Cancer Center, NY, USA

Marie Bakitas Department of Anesthesiology, Section of Palliative Medicine, Dartmouth-Hitchcock Medical Center, Lebanon, NH; The Dartmouth Institute for Health Policy and Clinical Practice, Dartmouth Medical School, Hanover, NH, USA

Results:

- Four themes: enhanced problem-solving skills, better coping, feeling empowered, and feeling supported.
- Three themes related to trial participation: helping future patients and contributing to science, gaining insight through completion of questionnaires, and trial/intervention aspects to improve.

Conclusions:

- The benefits of the intervention and the positive aspects of trial participation outweighed trial “burdens” (‘not needed when feeling well’)
- Raised important questions: When should a palliative care intervention be initiated? How to include self-care and healthy living in addition to palliative content?

UNDERSTANDING PATIENT VIEWS ON ENABLE

Theme	Exemplar quote
Themes Related to Intervention Participation	
Enhanced problem-solving	“I think the steps in...decision making and communication...it was most helpful dealing with my husband and the problem I was having with, you know, juggling between him and an oncologist, and what my needs were and how needy he was....” (P14 Intervention; GI)
Better coping	“I thought, number one, there’s a listing in the back (of “Charting your Course”) that gives you a lot of outside organizations that can help or give you information....Also, some of the things to help you think through, for example, if you’re diagnosed with an end stage illness, what should you be thinking about, what do you think you ought to be doing right now in preparation?” (P23 Intervention; Lung)
Feeling empowered	“She’s (nurse educator) given me that nudge when I’ve had some problems. I’ll go back to the doctor and talk with him or something like that.” (P24 Intervention; GU)
Feeling supported, reassured, and hopeful	“It’s been a supportive mechanism, you know, because, for example, when the nurse and I would talk on the phone, she knew what was going on with me. It wasn’t like I had to explain everything, so that was very supportive.” (P23 Intervention; Lung)

UNDERSTANDING PATIENT VIEWS ON ENABLE

Themes Related to Trial Participation

<p>Helping future patients and contributing to science (altruism)</p>	<p>"I believe that when somebody, for example in my situation, finds out you have a terminal disease, yeah, it's rocky and it's emotional, but my thought was, if the study would help other people, that's a good thing." (P23 Intervention; Lung)</p>
<p>Completing questionnaires provided insights into condition and emotions</p>	<p>"I felt in some way, like somebody was hearing my individual situation. It, it was interesting to fill it out. It was sort of like, you know, instead of keeping a diary... 'How has your last week actually been?' Well, it's sort of nice to sit down and think about it." (P14 Intervention; GI)</p>
<p>Trial/Intervention Aspects to Improve</p>	<p>Control patient "I was hoping that it would give me some support, I don't really feel that it has." (P28 Control; Breast)</p> <p>Didn't apply to me: "Actually up until a couple of months ago, a lot of the stuff that was in the book wasn't even appropriate. I mean, it wasn't necessary for me...at first I couldn't relate to a lot of the stuff." (P17 Intervention; GI)</p> <p>Reminded me about illness "I did sort of let go for a while on participation, and it was more because I was having too much fun, and I didn't want to be a patient that day. I don't want to be a patient every day of my life. And, so the less time I have with the medical profession, the more I feel like a normal person." (P14 Intervention; GI)</p>

ENABLE III Study Modifications

JUSTIFICATION FOR PALLIATIVE CARE STUDIES

JUSTIFICATION FOR QUESTIONNAIRES

FAST TRACK DESIGN

DELAYED TIMING

SELF-CARE CONTENT

“There were more decisions and more options than just yes or no”: Evaluating a decision aid for advanced cancer patients and their family caregivers

MARIE BAKITAS, D.N.S.C., C.R.N.P.,^{1,2*} J. NICHOLAS DIONNE-ODOM,¹
LISA JACKSON, B.A.,³ JENNIFER FROST, M.S., R.N.,¹ MARGARET F. BISCHOFF,¹
AND ZHONGZE LI, M.S.³

Table 5. *How was receiving the program timed?*

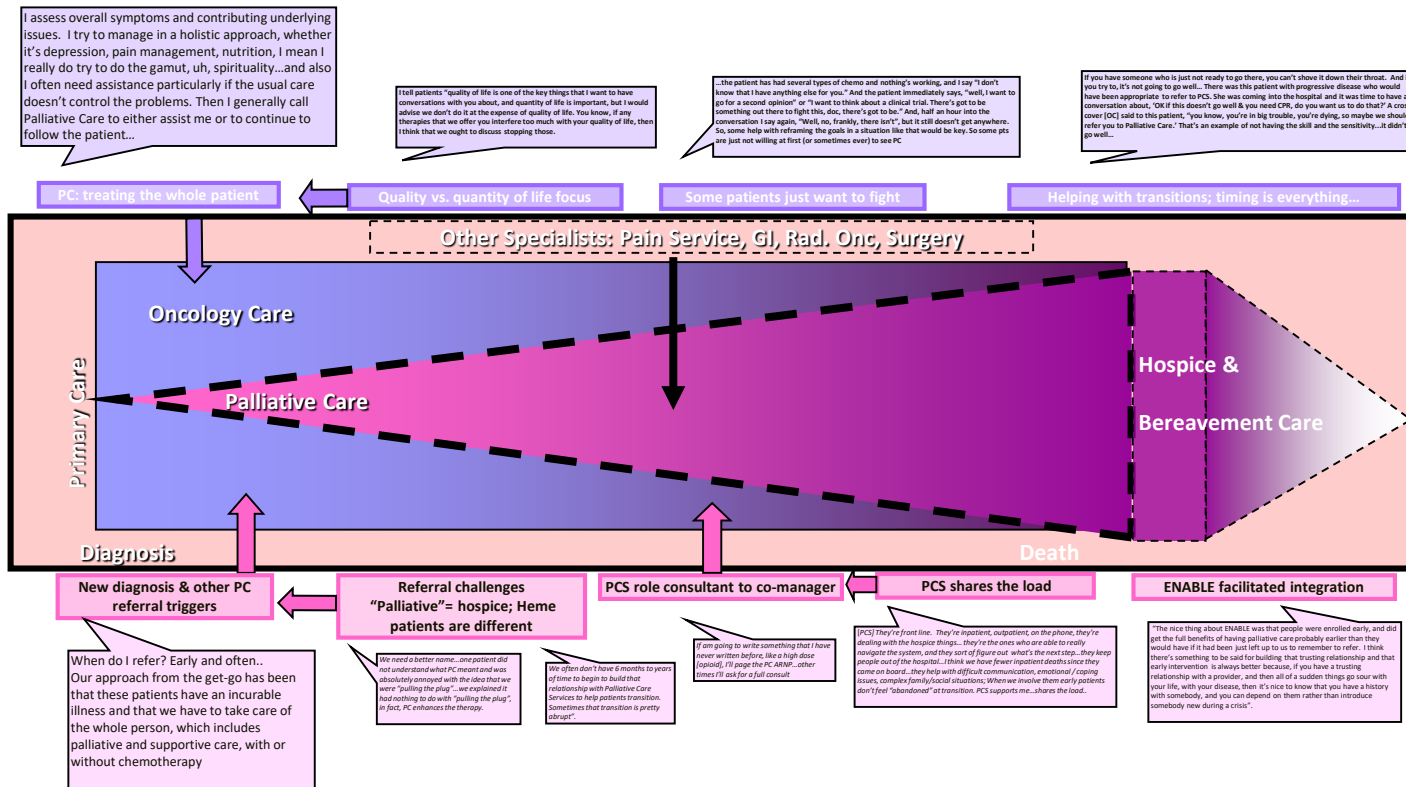
Theme	Exemplar quote
Right time (49%)	“I think I got it at pretty much the right time. I wouldn’t have wanted it five or six years ago. I was not ready to listen to any of that stuff, but like the people in the video, I’m getting a little tired. So now I’m more accepting to listen to this, where I wasn’t before, because I thought I was indestructible ... after having two stents, brain surgery, and a collapsed lung, I know I’m not indestructible ... it kind of hit home.” (ID 178, male, renal cancer, age 59)

Engaged in care planning decisions including family members in decisions
“... maybe there might be a more of an urgency to get some of the paperwork done, such as the will ... a DNR. It should be done sooner rather than later.” (ID 123, male, lung cancer, age 50)
“... I didn’t think about it. Do I want to be stuck on life support? No! That’s the way I feel about [watching the DVD] we signed proxies, and we have a living will ... It was informative, and I thought about it.” (ID 182, male, pancreatic cancer, age 70)
“... or more [with the program] ... I think you need to just jump in and do it ...

Became aware of different options (such as palliative and hospice care)

“You know, part of me looks at that situation there [on the DVD], and not that I’m in any position right now where I even need a feeding tube, but do I want to have one? Probably not, but you know, if I got pneumonia and, whatever, you know I just—I think it was a little more gray than black and white, and I just felt like there were more decisions and more options than just yes, or no, or this or that. I guess that was very helpful.” (ID 58, female, breast cancer, age 49)

Oncology Clinician's Views of Palliative Care for Advanced Cancer Patients



Early Palliative Care ENABLE Trials (Cancer)

From Stakeholder Need to Effectiveness & Implementation Research

**Stakeholder
Development**

**WHO Guidelines, SUPPORT Study
Results, Patient, Family, Clinician
Focus Groups**

**Project ENABLE
In-Person Demonstration
Project
(RWJF)
1999-2001**

**Effectiveness
Research**

**ENABLE II
Solid
Tumor/Telehealth
Efficacy RCT
(NCI)
2003-2008**

**ENABLE III
Solid Tumor, Heme & Caregiver
Effectiveness RCT
(NINR)
2003-2009**

**Implementation &
Optimization
Research**

**IMPLEMENTATION
ENABLE IV (4 site)
(ACS) 2012-2017
ENABLE-NCORP
48 site VLC vs TA
(NCI Funded Oct 2018)**

**ENABLE OPTIMIZATION
Rural, Low Income
UAB/GHSCI
(NCI-Submitted 9/18)**

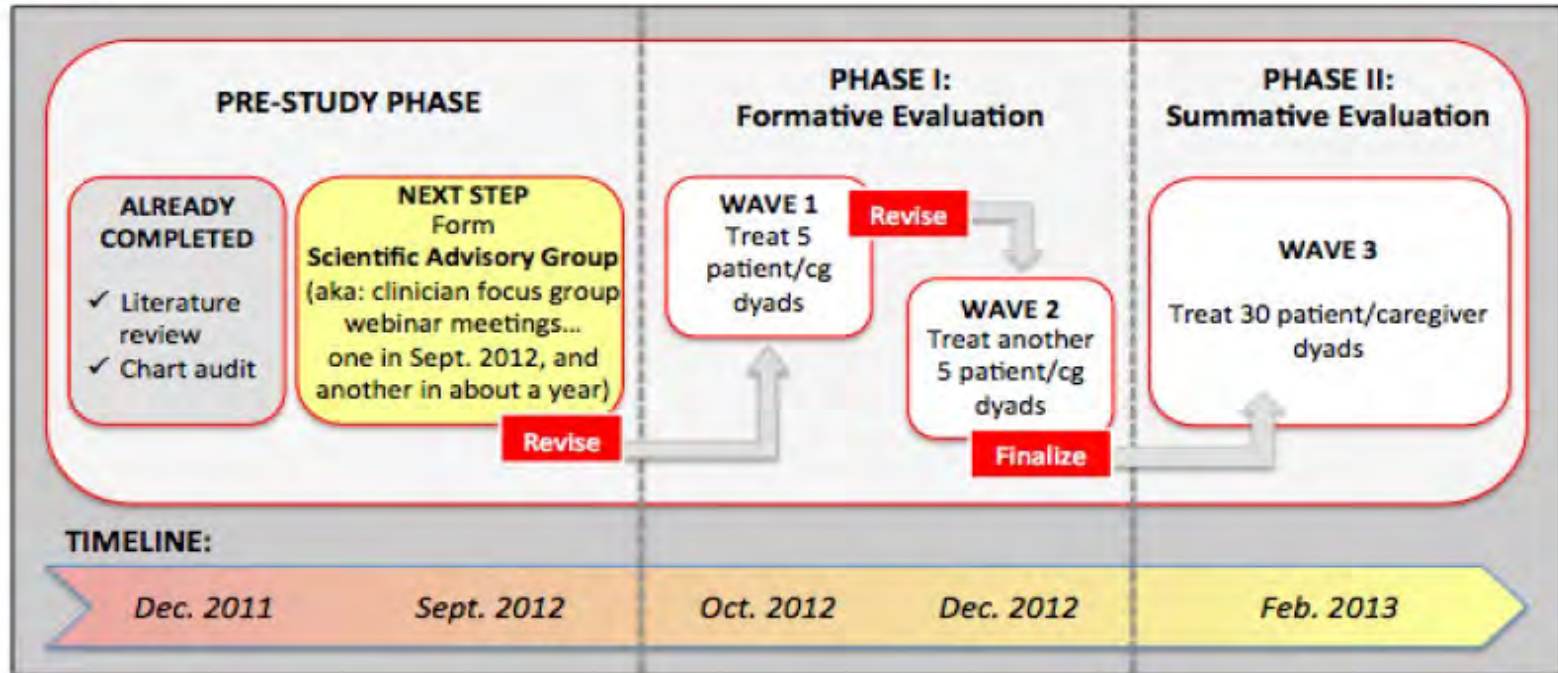
JOURNAL OF PALLIATIVE MEDICINE
Volume 17, Number 9, 2014
© Mary Ann Liebert, Inc.
DOI: 10.1089/jpm.2013.0680

Translating and Testing the ENABLE: CHF-PC Concurrent Palliative Care Model for Older Adults with Heart Failure and Their Family Caregivers

J. Nicholas Dionne-Odom, PhD, RN,¹ Alan Kono, MD,² Jennifer Frost, MSN, RN,² Lisa Jackson, BSN,³
Daphne Ellis, AA,² Ali Ahmed, MD, MPH,⁴ Andres Azuero, PhD,¹ and Marie Bakitas, DNSc, CRNP¹

TRANSLATING ENABLE FROM CANCER TO HEART FAILURE

STUDY DESIGN:



WAVE 1 SATISFACTION INTERVIEWS

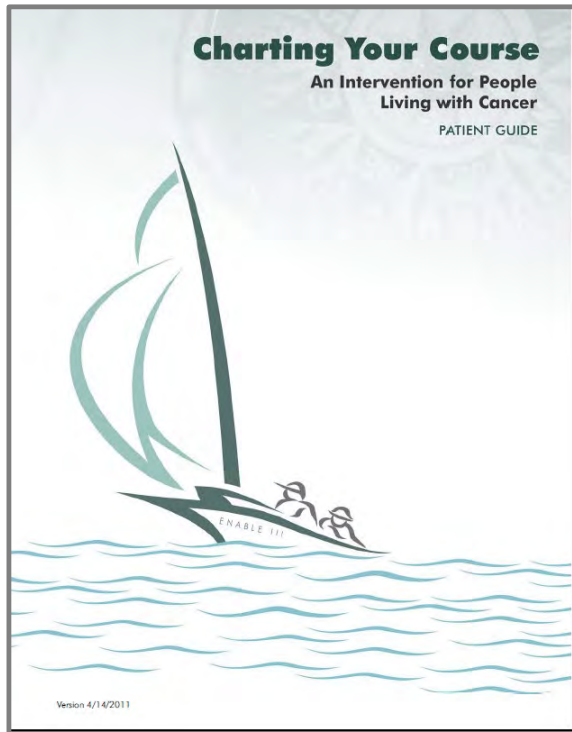
Booklet ➤ “too dense” “need more graphics”

Content ➤ “need more content for people feeling well”
➤ Shorten chapter length (Literacy)

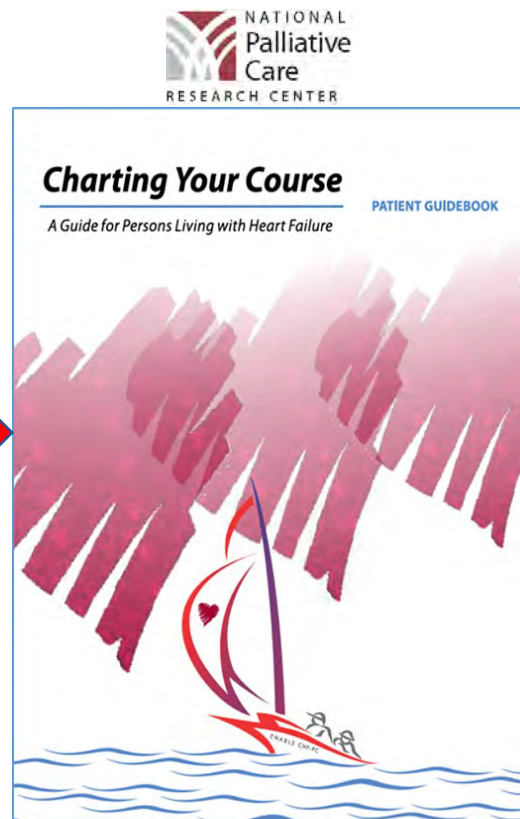
Timing ➤ Wished they had the program sooner; already had learned some of the content by trial and error.

Nurse coach ➤ Liked having someone to vent to; to help put things in perspective

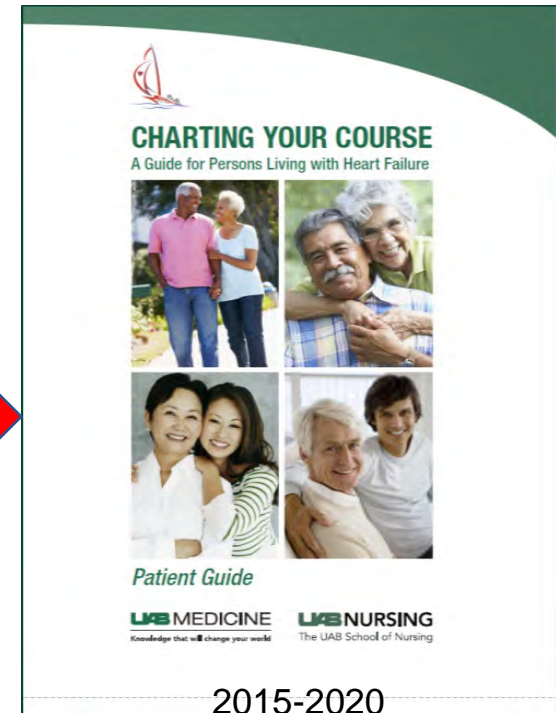
CHARTING YOUR COURSE GUIDEBOOKS MORE SELF-CARE, DIVERSITY, PATIENT-FRIENDLY, LITERACY



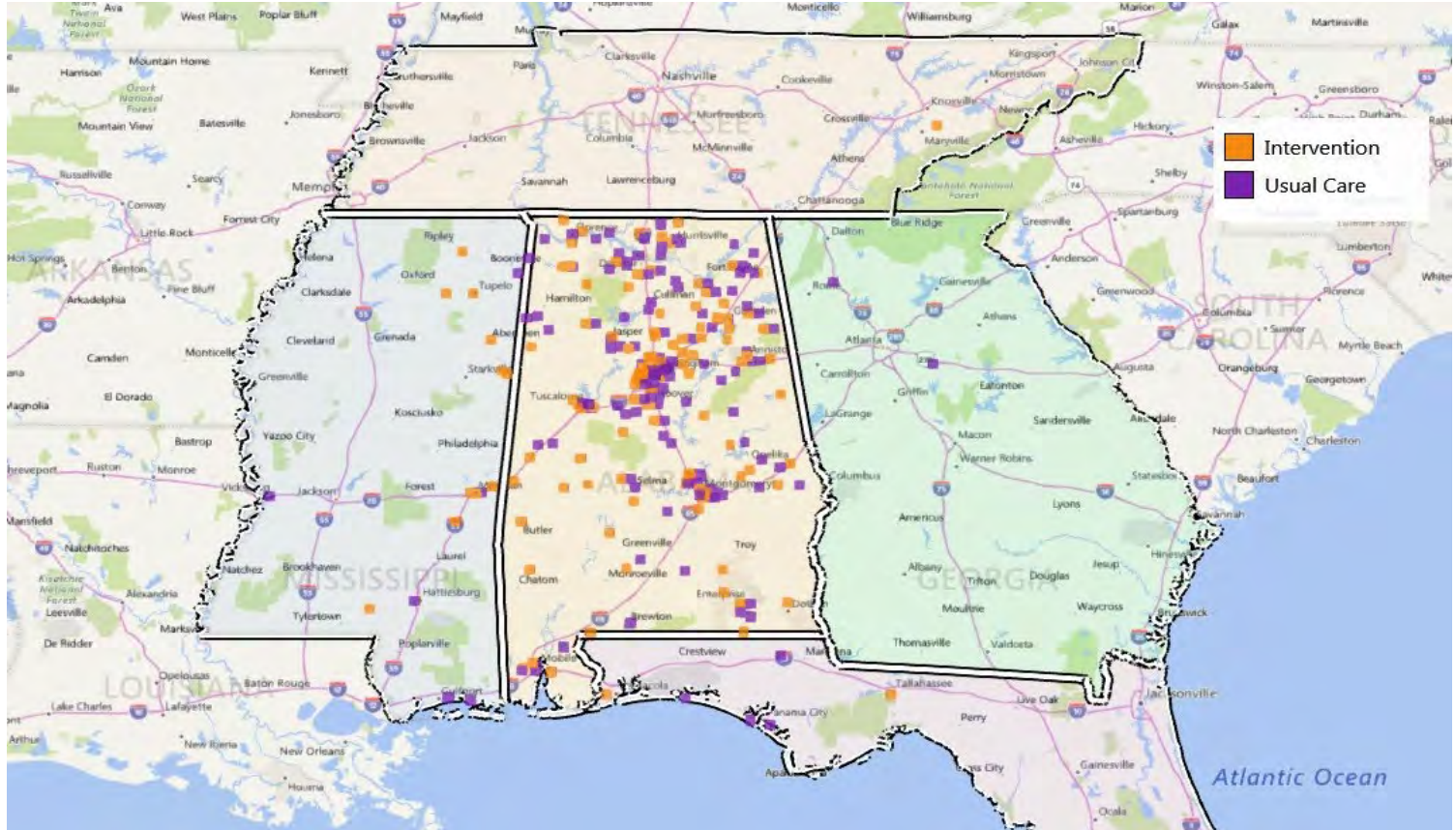
2008-2013



2011-2015



ENABLE INCREASES ACCESS TO SPECIALTY PALLIATIVE CARE



REACH OF NINR R01 ENABLE CHF PC (N=415 PARTICIPANTS) LOCATIONS

EARLY PALLIATIVE CARE ENABLE TRIALS (NON-CANCER)

FROM TRANSLATION & FORMATIVE EVALUATION TO EFFECTIVENESS & IMPLEMENTATION RESEARCH

Translational Evaluation

AHA Guidelines, Literature & Chart Reviews, Patient, Family, Clinician Focus Groups

ENABLE CHF-PC
Formative Evaluation Pilot
(Dartmouth SYNERGY)
2010-2013

Effectiveness Research

ENABLE CHF-PC
2-site (NH/AL) Pilot
(NPCRC)
2013-2015

ENABLE CHF-PC
Effectiveness RCT
(NINR)
2015-2020

MOST, Hybrid & Implementation Research

ENABLE COPD (EPIC)
Single Arm Pilot
Iyer
(UAB PREP & PCOR K 12)
2016-2019

ENABLE
CORNERSTONE
Cancer Caregivers
Dionne-Odom
(NINR K99
NR015903)
2016-2021

AN UPSTREAM PALLIATIVE CARE INTERVENTION FOR RURAL ADVANCED CANCER FAMILY CAREGIVERS IN THE DEEP SOUTH

(PI: Dionne-Odom; Funding: NINR R00NR015903; National Palliative Care Research Center)

Specific Aim 1 (K99 phase): Tailor telehealth intervention outline for Southern rural-dwelling advanced cancer family caregivers

Specific Aim 2 (R00 phase): Evaluate acceptability of a newly developed intervention and the feasibility of enrolling and retaining 60 participants into a small-scale RCT for 24 weeks

Specific Aim 3 (R00 phase): Evaluate the *potential* efficacy of the newly developed FCG intervention compared to usual care



AN UPSTREAM PALLIATIVE CARE INTERVENTION FOR RURAL ADVANCED CANCER FAMILY CAREGIVERS IN THE DEEP SOUTH

(PI: Dionne-Odom; Funding: NINR 1K99R015903; National Palliative Care Research Center)

2-phase formative evaluation study

Phase 1/Aim 1: Conduct interviews with lay navigators, family caregivers and patients to elicit feedback on an intervention outline

Phase 2/Aims 2-3 (enrollment beginning Oct. 2018): Small scale RCT of newly-developed intervention



PHASE 1/AIM INTERVIEWS

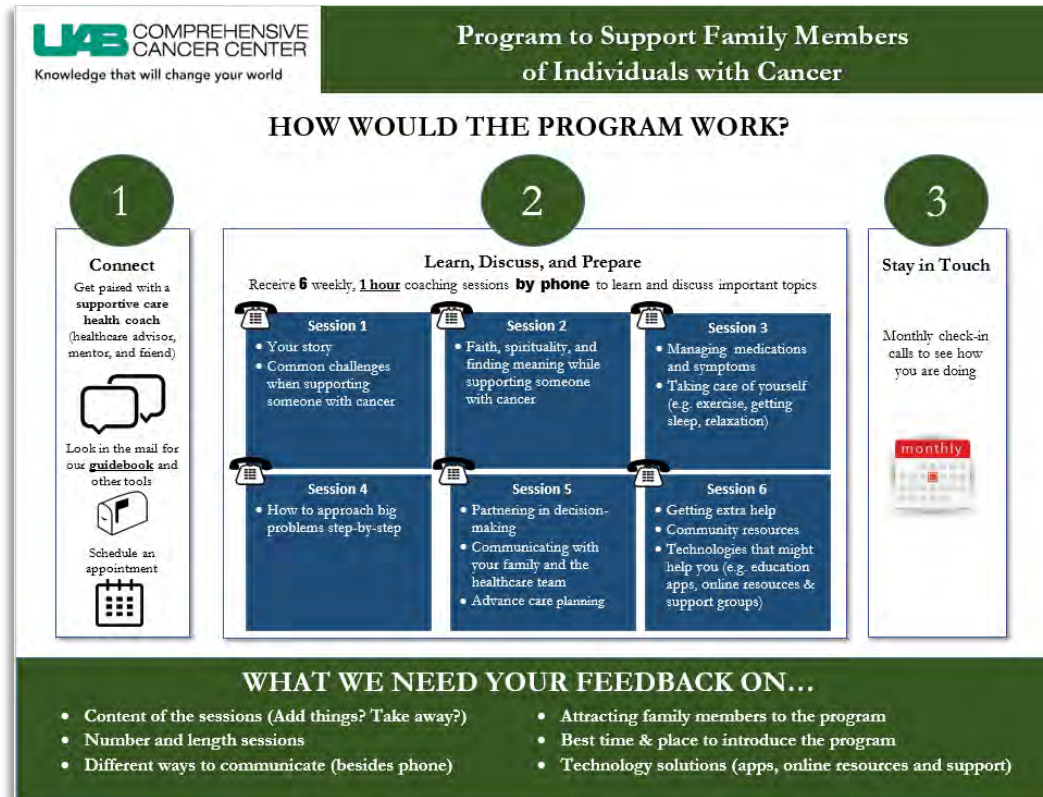
Part 1: Experiences and challenges of caregivers

Part 2: Role of caregivers in assisting with prospective decision-making

Part 3: Specific feedback on intervention

Interviews complete:

26 navigators, 20 caregivers, 18 patients



PHASE 1/AIM 1 PRELIMINARY FINDINGS

Qualitative themes

Flexibility needed in number and length of sessions

Flexible content based on continuous assessment

Keep things simple and visual, technology okay but internet access is problematic in rural areas

Face-to-face contact to establish relationship

Mixed views on navigator role

Spirituality/faith important but should not be overarching theme

Implications for intervention based on qualitative themes

20-60 minute sessions with opportunity for additional sessions

Mixed in-person + telephone contact (at least 1 in-person visit)

Adaptive content based on continuous assessment

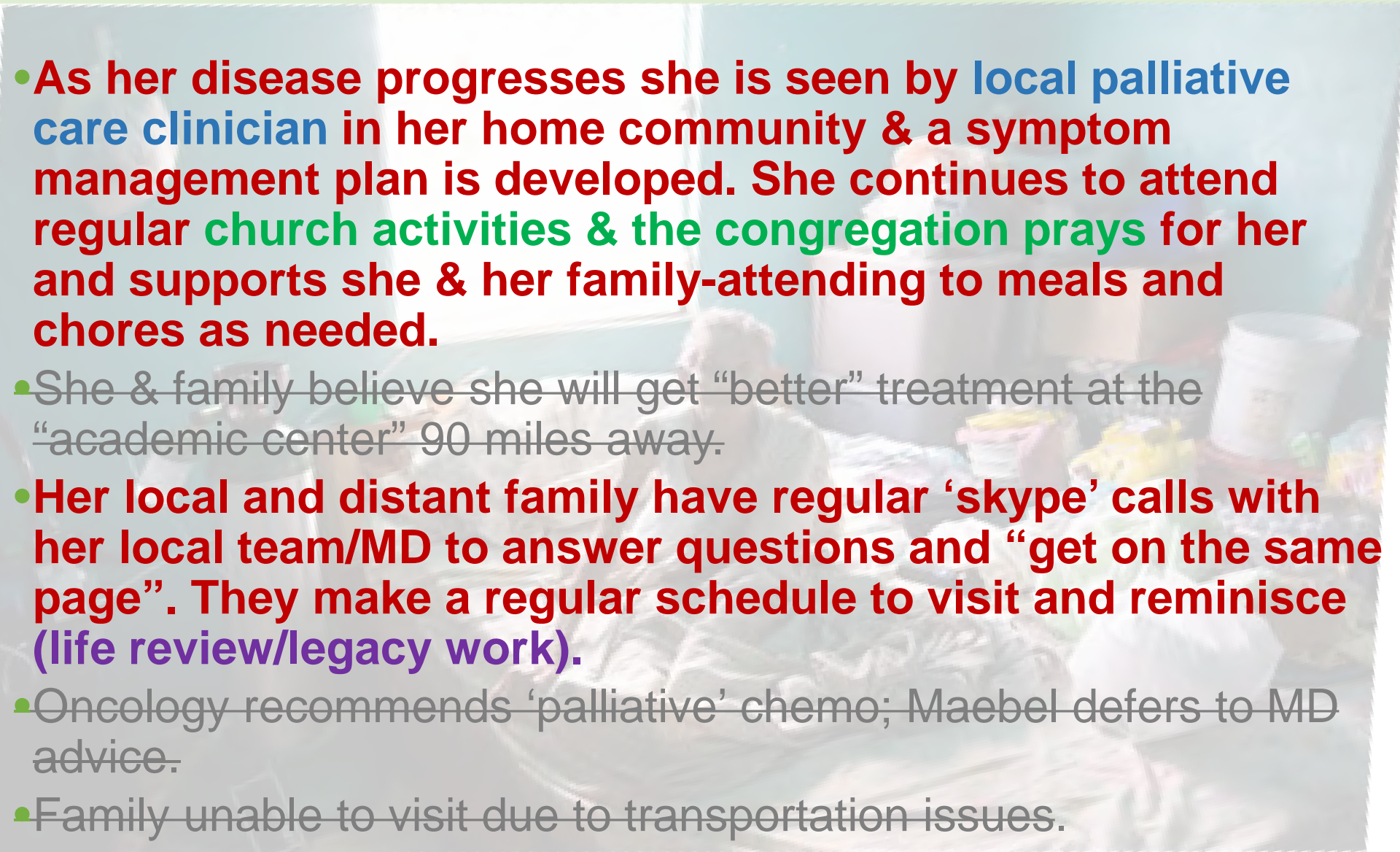
Navigator-led with enhanced training and weekly supervision

Therapeutic alliance building to enhance behavioral activation

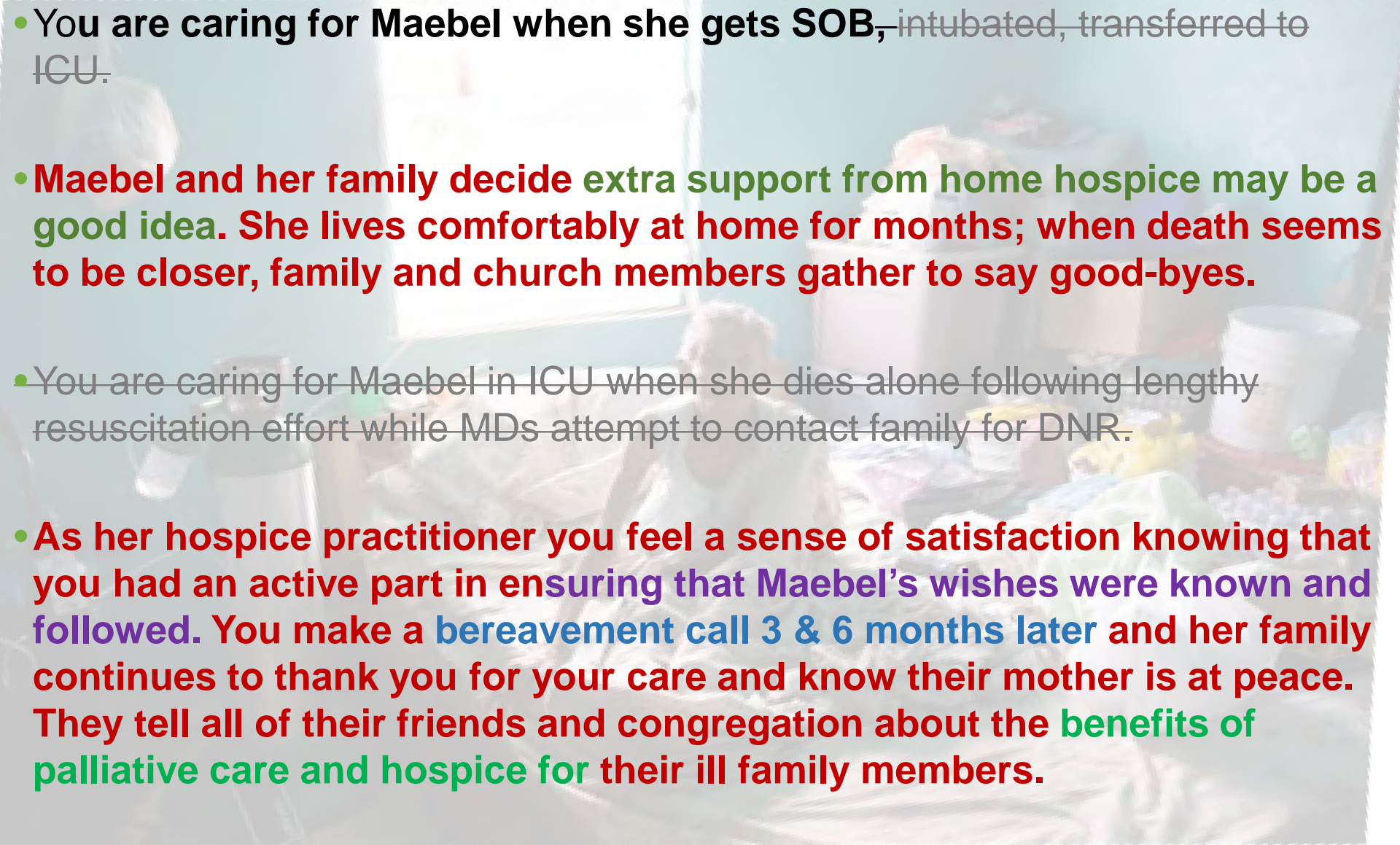
CREATING A BRIGHTER FUTURE FOR RURAL PALLIATIVE CARE

- **Maebel is 78 yo African American woman with recurrent breast cancer, lymphangitic pulmonary metastases & dyspnea admitted to local critical access hospital. Baptist, 5 children, 10 grandchildren, 3 great-grandchildren all but 1 live 'up north'.**
- **She and 1 her local child are referred to early palliative care. They work with nurse coach to identify Maebel's goals & values if her disease progresses including local health care/hospice/ home care resources.**
- **Maebel learns about and has conversations with her family about her wishes. She identifies her oldest son (caregiver) as her DPOA for health care and completes an advance directive which is placed in her medical record and copies are given to her MDs and family members.**

CREATING A BRIGHTER FUTURE FOR RURAL PALLIATIVE CARE

- 
- **As her disease progresses she is seen by local palliative care clinician in her home community & a symptom management plan is developed. She continues to attend regular church activities & the congregation prays for her and supports she & her family-attending to meals and chores as needed.**
 - ~~She & family believe she will get “better” treatment at the “academic center” 90 miles away.~~
 - **Her local and distant family have regular ‘skype’ calls with her local team/MD to answer questions and “get on the same page”. They make a regular schedule to visit and reminisce (life review/legacy work).**
 - ~~Oncology recommends ‘palliative’ chemo; Maebel defers to MD advice.~~
 - ~~Family unable to visit due to transportation issues.~~

CREATING A BRIGHTER FUTURE FOR RURAL PALLIATIVE CARE

- 
- You are caring for Maebel when she gets SOB, ~~intubated, transferred to ICU.~~
 - **Maebel and her family decide extra support from home hospice may be a good idea. She lives comfortably at home for months; when death seems to be closer, family and church members gather to say good-byes.**
 - ~~You are caring for Maebel in ICU when she dies alone following lengthy resuscitation effort while MDs attempt to contact family for DNR.~~
 - **As her hospice practitioner you feel a sense of satisfaction knowing that you had an active part in ensuring that Maebel's wishes were known and followed. You make a bereavement call 3 & 6 months later and her family continues to thank you for your care and know their mother is at peace. They tell all of their friends and congregation about the benefits of palliative care and hospice for their ill family members.**

- **TOGETHER WE CAN DO IT!!!**



ACKNOWLEDGEMENTS

- **ENABLE Research Team**
 - Engler, Ejem, Dionne-Odom
 - Wells, Sockwell, Keebler, Tims
 - Pamboukian, Tallaj, CVCC, Durant,
 - Schach, Mapson, CD, CY Johnson-Recruitment & Retention Shared Facility
 - Students-Beasley, Stockdill

- **UAB School of Nursing**
 - Harper, Meneses, Wiser, Davis, De La Piedra - ORS Grants Team
 - Palliative Care Specialty Nursing Tract Team- Edwards, Taylor, Dionne-Odom, Currie

- **UAB Center for Palliative & Supportive Care Team**
 - Tucker, Elk
 - Nichols, Howell, Palmore-UAB Hospital PCCU & Consult Teams
 - Kvale, Hicks, Crump-Palliative and Supportive Care Clinic Teams
 - Swetz, Hogan, Mahone, Burgio, Callans VA Safe Harbor Clinical & Research Teams
 - Nichols, Barnett, Perna, et al. Children's Hospital of Alabama
 - Barnett-Fellowship