THE UNIVERSITY OF ALABAMA AT BIRMINGHAM

Knowledge that will change your world

Access and Availability of Palliative Care Models

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School of Nursing/Department of Medicine
Associate Director, Center for Palliative and Supportive Care

Cancer Care in Low Resource Areas
National Cancer Policy Forum
November 14, 2016

Conflict of Interest

I have no conflicts of financial interest to disclose .

Funding Sources Disclosures

American Cancer Society

National Cancer Institute

National Institute of Nursing Research

Department of Defense, United States of America

PROMOTING EXCELLENCE
IN END-OF-LIFE CARE

A NATIONAL PROGRAM OF
THE ROBERT WOOD JOHNSON FOUNDATION

National Palliative Care Research Center

ONS Oncology Nursing Society

CALGB Tomorrow's Cancer Treatments Today

NP HF Nurse Practitioner Healthcare Foundation

Yale School of Nursing • Leadership in Research Education • Clinical Practice

Dartmouth-Hitchcock Norris Cotton Cancer Center

The Byrne Foundation

UAB School of Nursing

Knowledge that will change your world

Knowledge that will change your world

Outline

I. Palliative Care in Low Resource Areas: Unique Access Challenges

II. Innovative Models/Strategies to Achieving Palliative Care Everywhere

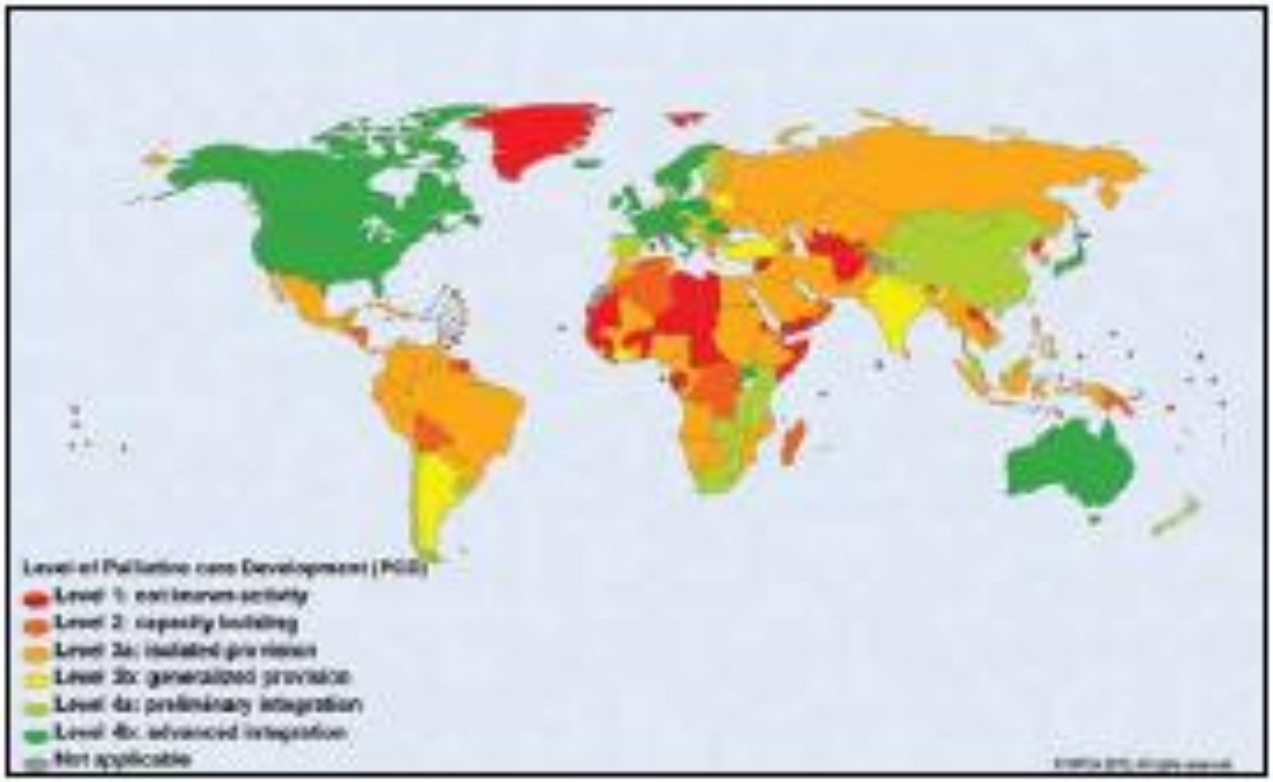
Outline

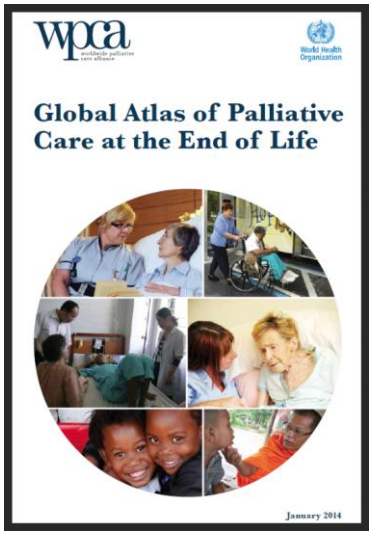
I. Palliative Care in Low Resource Areas: Unique Access Challenges

II. Innovative Models/Strategies to Achieving Palliative Care Everywhere

Palliative Care is Poorly Integrated Globally

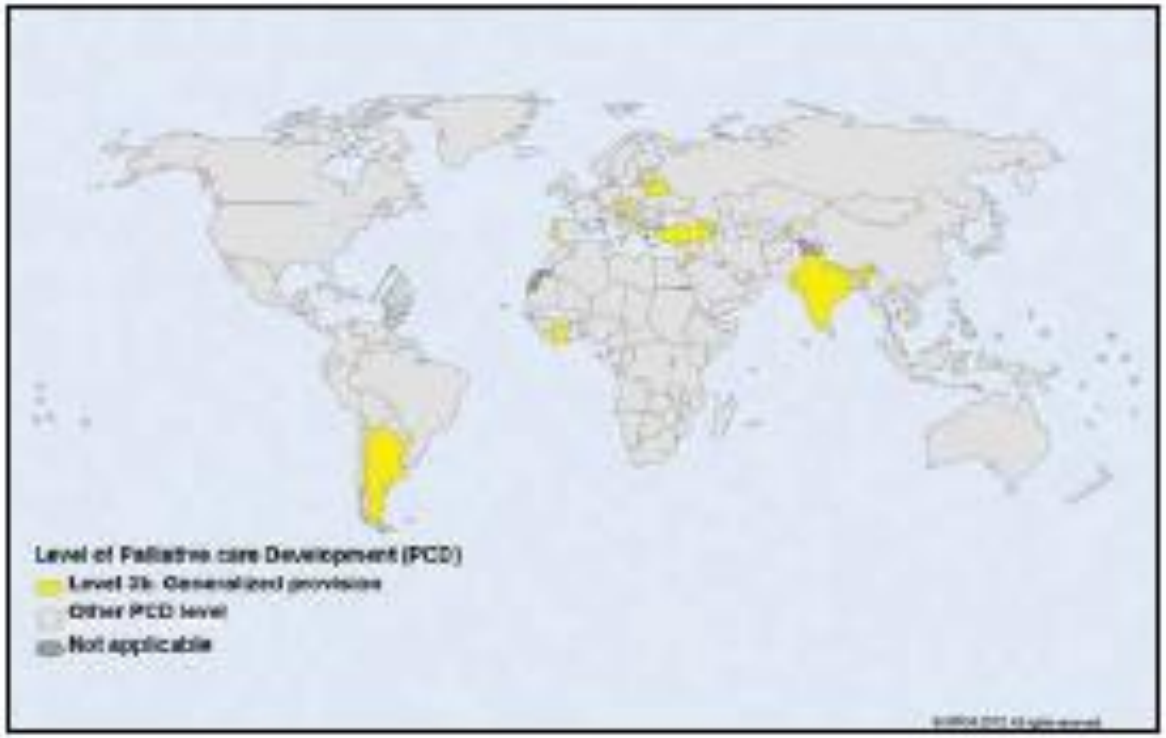
Figure 37
Levels of palliative care development – all countries

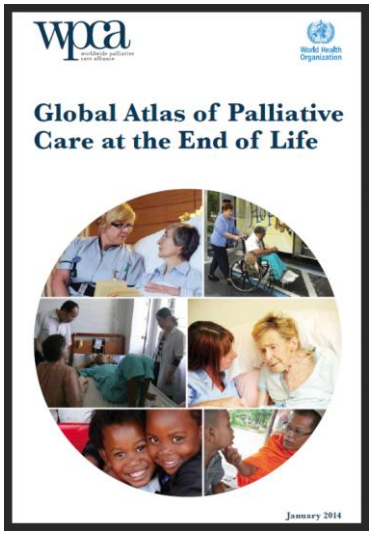




Palliative Care is Poorly Integrated Globally

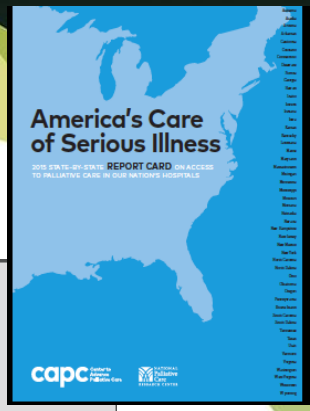
Figure 34
Countries with generalised provision of palliative care (Level 3b)

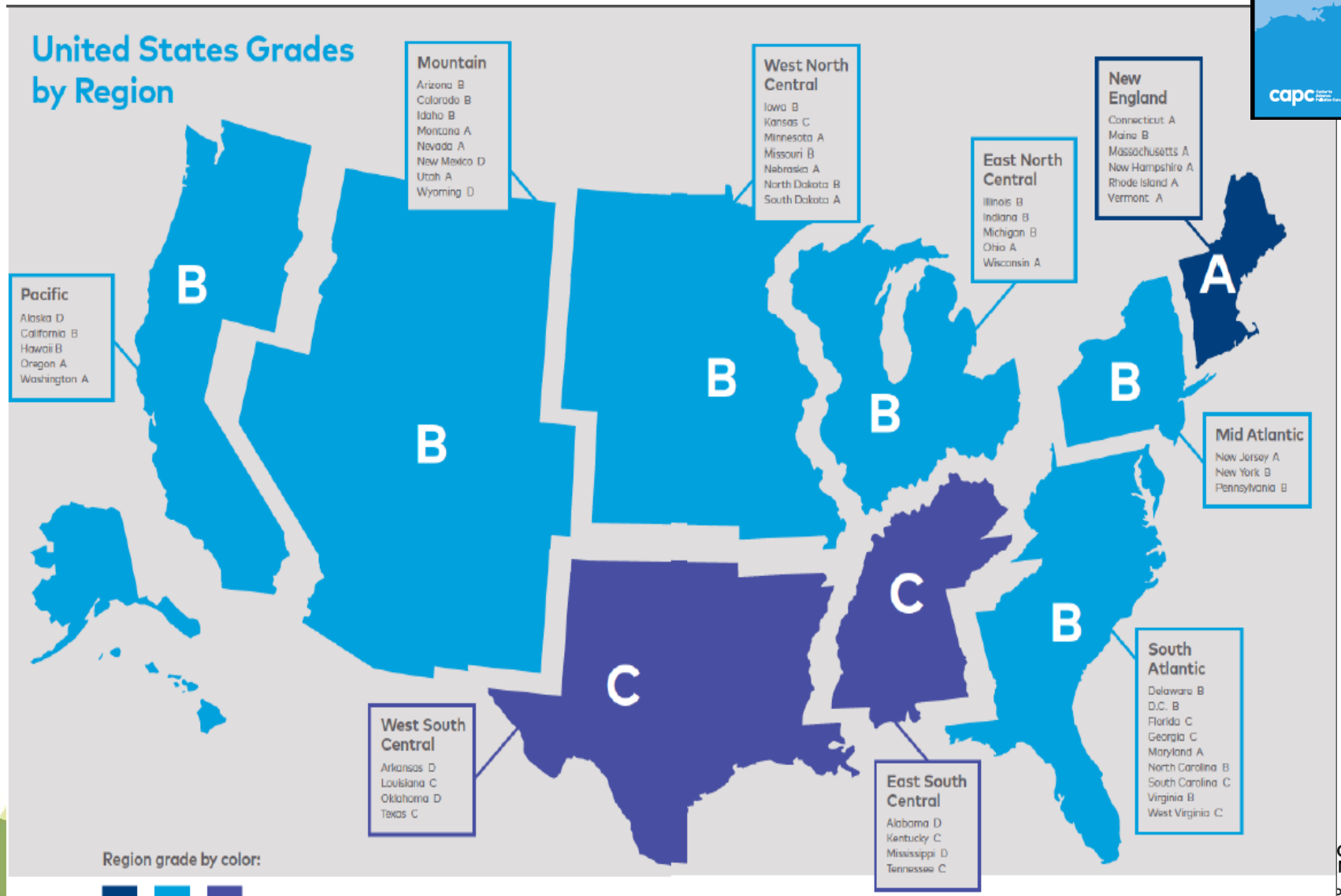




Group 4b Advanced integration N = 20 (8.6%)	Australia, Austria, Belgium, Canada, France, Germany, Hong Kong, Iceland, Ireland, Italy, Japan, Norway, Poland, Romania, Singapore, Sweden, Switzerland, Uganda, United Kingdom, United States of America.

2015 State-by-State Report Card Shows Inconsistent Uptake





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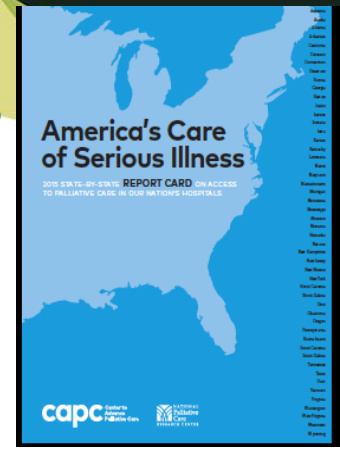
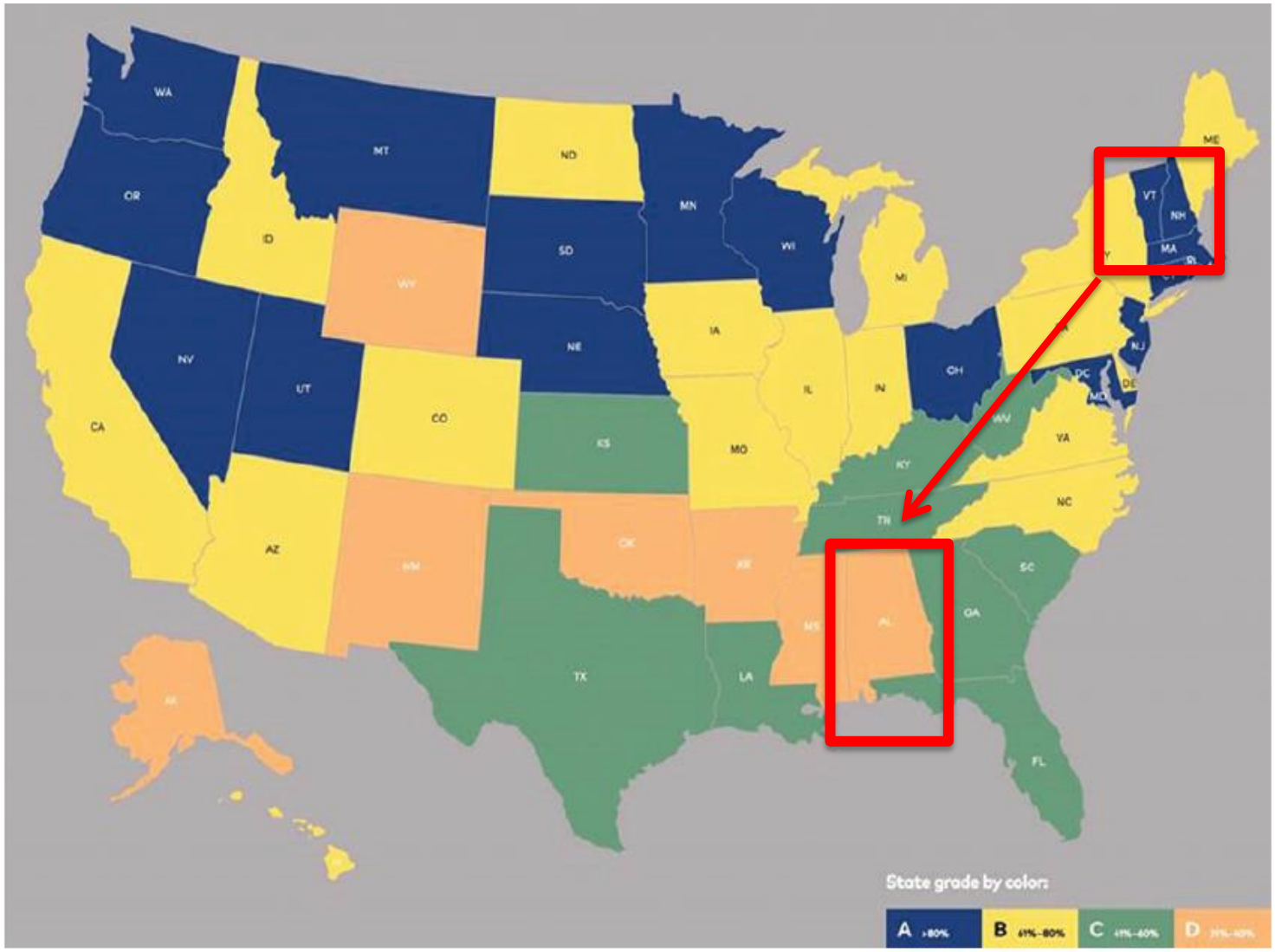
2015 State-by-State Report Card Shows Inconsistent Uptake





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What's Going On?

- PATIENT/FAMILY ISSUES
- PROVIDER ISSUES
- HEALTH SYSTEM ISSUES

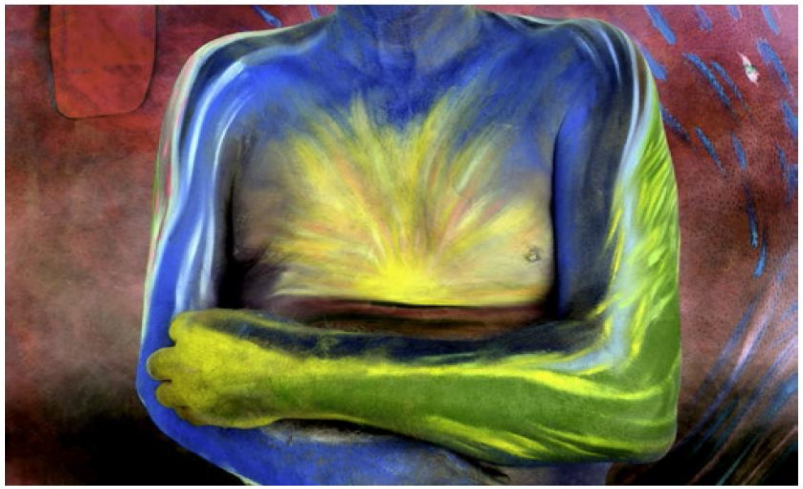


Photo courtesy of Lisa Scholder. *Masculine*, 14" × 22".

Cancer Control
Journal of the Moffitt Cancer Center

Integrating palliative care has not always extended to rural areas; however, some research is focusing on future progressive solutions.

Systematic Review of Palliative Care in the Rural Setting

Marie A. Bakitas, DNSc, CRNP, Ronit Elk, PhD, Meka Astin, MPH, Lyn Ceronsky, DNP, GNP, Kathleen N. Clifford, MSN, FNP-BC, J. Nicholas Dionne-Odom, PhD, RN, Linda L. Emanuel, PhD, MD, Regina M. Fink, RN, PhD, Elizabeth Kvale, MD, Sue Levkoff, ScD, MSW, Christine Ritchie, MD, MSPH, and Thomas Smith, MD

450 Cancer Control October 2015, Vol. 22, No. 4

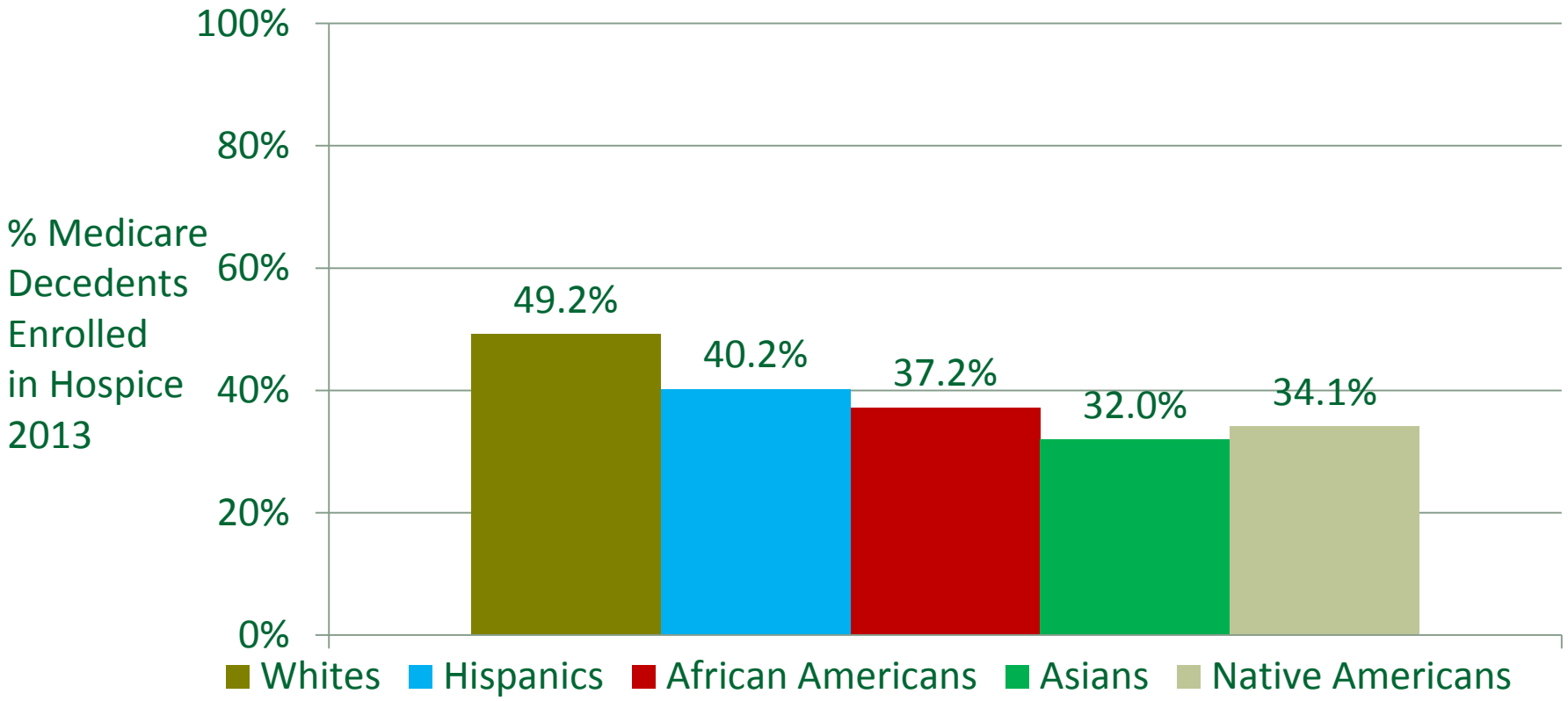
Unique Access Challenges

Patient Issues

- Complex confluence of poverty, education/health literacy, higher morbidity/mortality rates
- Mistrust of medical system & ‘outsiders’
- Cultural/spiritual beliefs
- Transportation issues

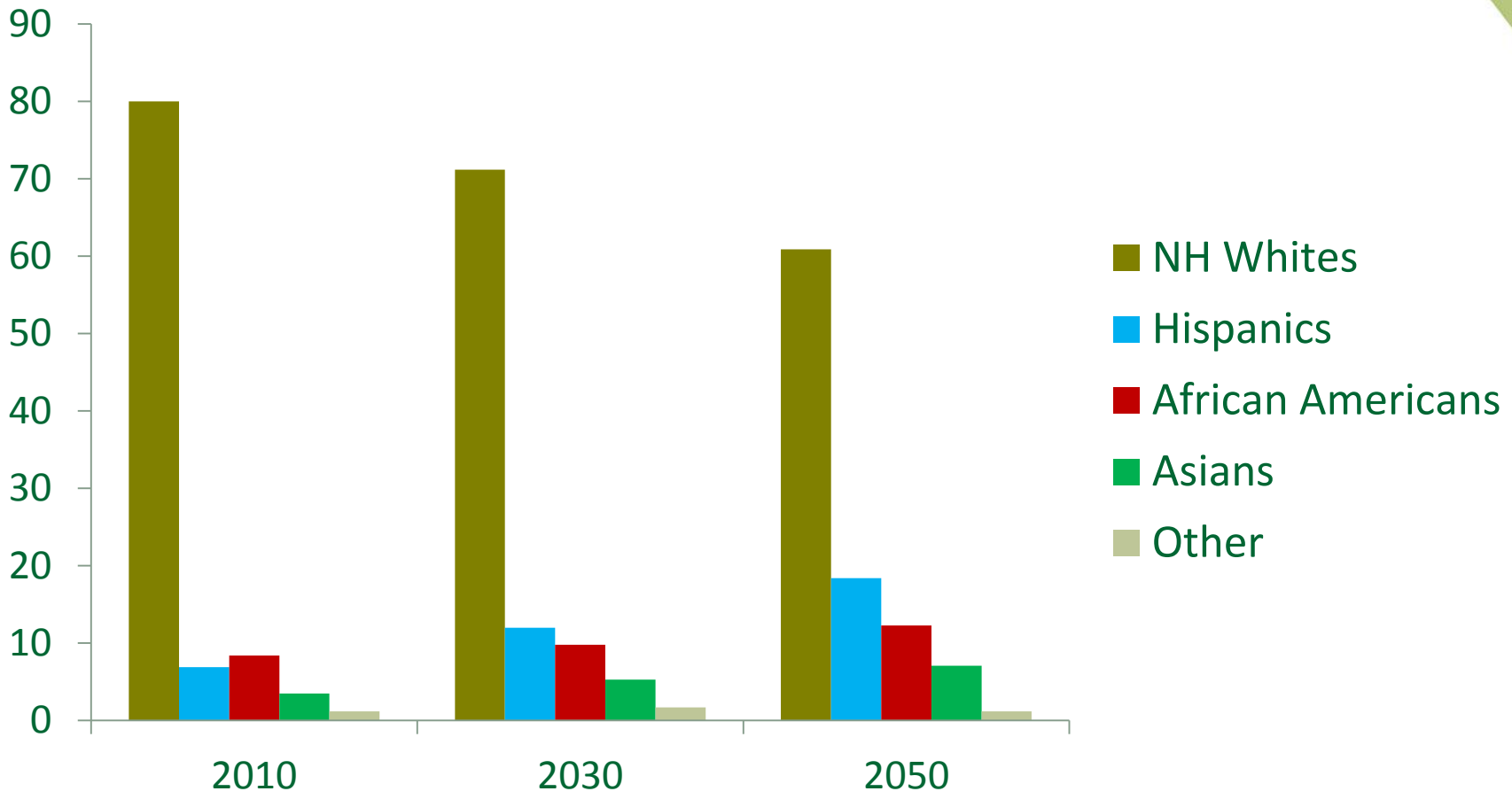
Johnson KS. et. al. *J Am Geriatr Soc.* 2005;53(4):711-719; Ernecoff NC, et al. *JAMA Intern Med.* 2015;175(10):1662-1669; Kwak J, Haley WE. *Gerontologist.* 2005;45(5):634-641; Mitchell BL, Mitchell LC.. *J Natl Med Assoc.* 2009;101(9):920-926. Fink et. al. JPM 2013; Ceronsky et al. 2013; CAPC Report Card 2011

Minorities Use Hospice at Lower Rates



Medpac 2015
Courtesy Kim Johnson, MD

Growth In Older Minorities



https://www.census.gov/prod/2014pubs/p25-1140.pdf

Courtesy Kim Johnson, MD

Unique Access Challenges

Provider Issues

- Few palliative care experts (only 22% of hospitals with <50 beds have PC & mostly in hospice)
- Few palliative/dying patients in rural practices
- Limited availability of palliative & culturally-based end-of-life care education
- Trust
- Fear of change

Fink et. al. JPM 2013; Ceronsky et al. 2013; CAPC Report Card 2011; Bakitas MA, Elk R, Astin M, et al. Systematic Review of Palliative Care in the Rural Setting. *Cancer Control.* 2015;22(4):450-464; Elliott AM, Alexander SC, Mescher CA, Mohan D, Barnato AE. Differences in Physicians' Verbal and Nonverbal Communication With Black and White Patients at the End of Life. *J Pain Symptom Manage.* 2016;51(1):1-8.

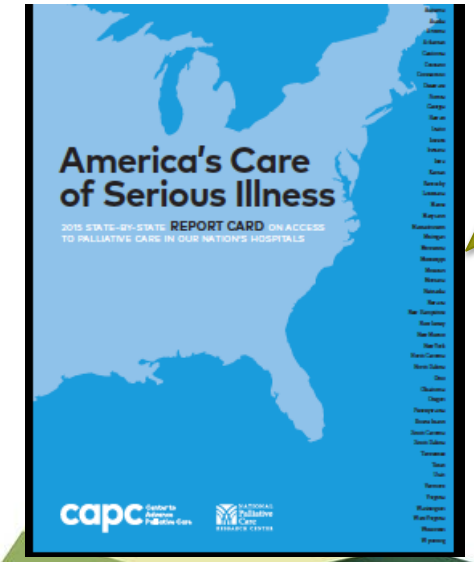
Unique Access Challenges

Practice/System Barriers

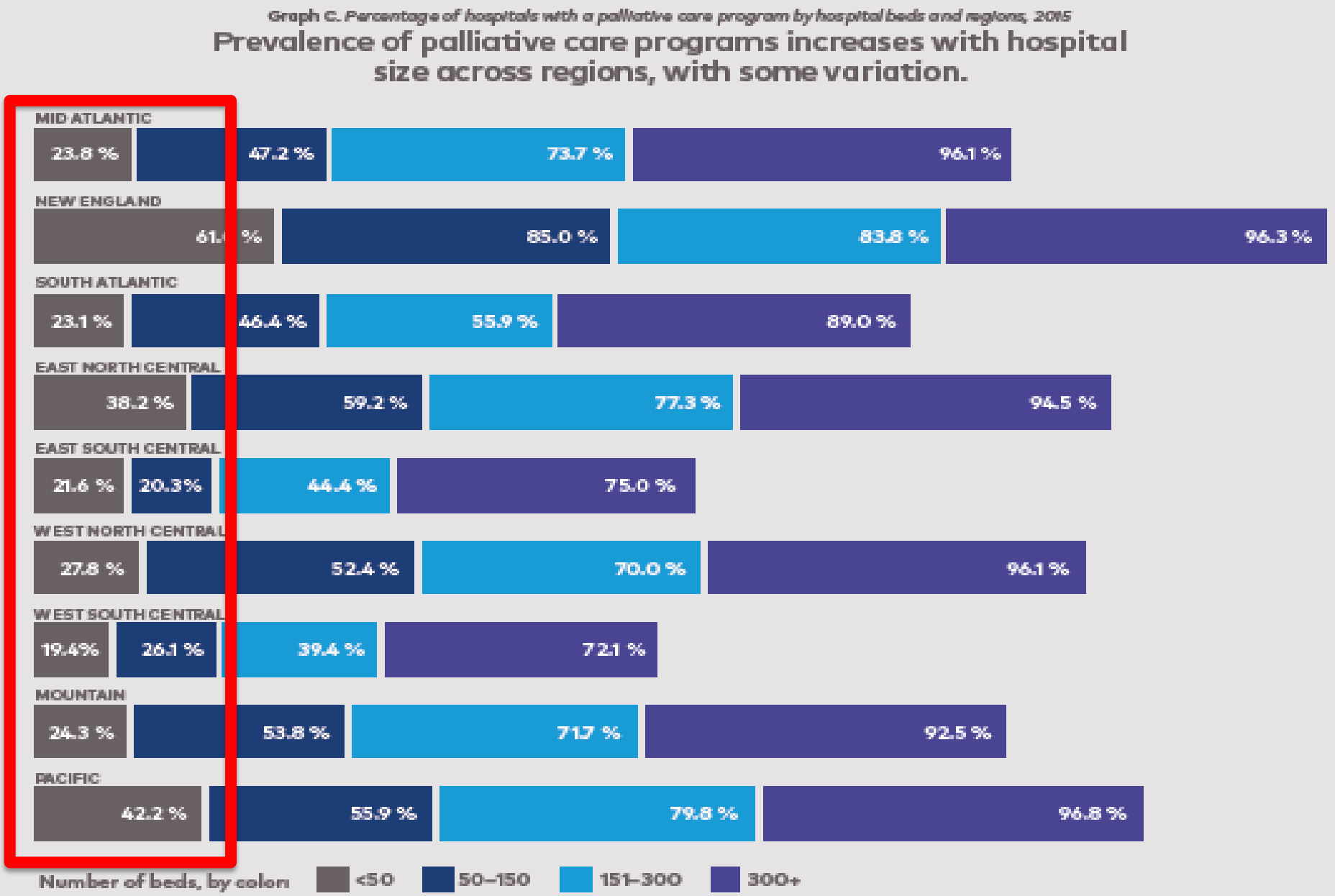
- Small, rural hospitals unable to support "traditional" palliative care team/services
- Poor communication/coordination between academic and rural community settings
- Practice/policy disincentives
  - Few (reimbursement) incentives to keep patients in local community (e.g. critical access hospitals)
  - Few evidence-based 'best practice' models for rural palliative care
    - no/limited mention of rural in National Consensus Guidelines or IOM "Dying in America" report

Institute of Medicine. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. Washington (DC)2014.

"Nationally, hospitals with fewer than 50 beds (29%) & sole community provider hospitals (45%) are less likely to provide palliative care."

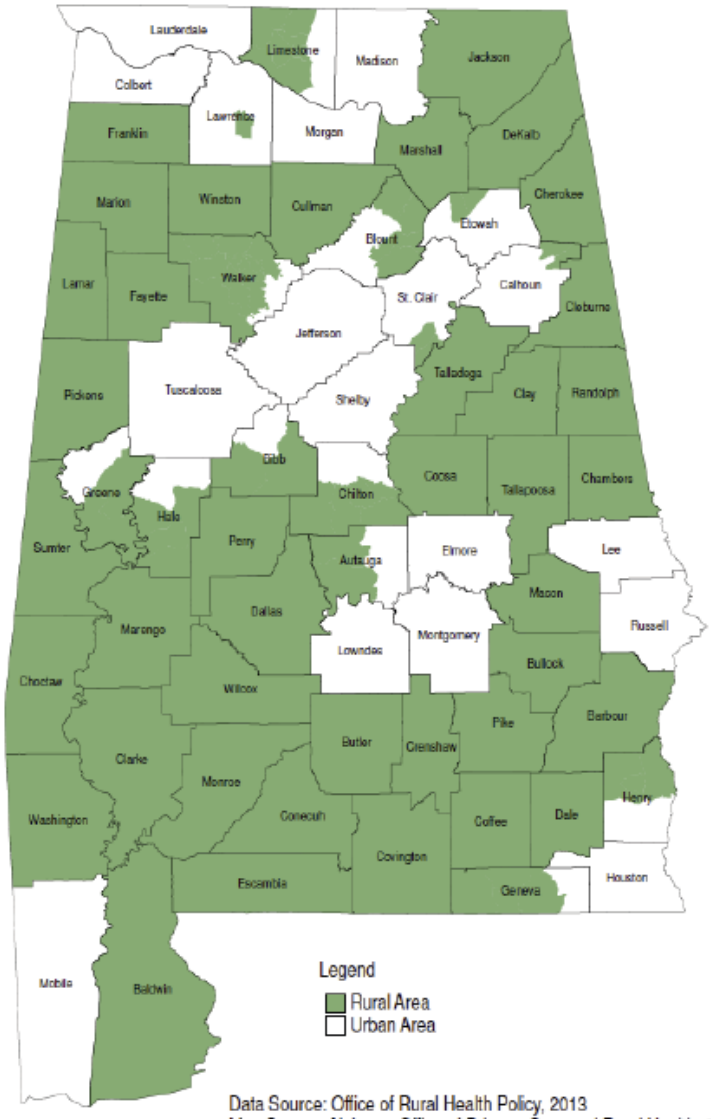


SIZE MATTERS !!!



ALABAMA CASE STUDY

Alabama's Rural Landscape
as Defined by Office of Rural Health Policy



Data Source: Office of Rural Health Policy, 2013
Map Source: Alabama Office of Primary Care and Rural Health, 2013

96%

of Alabama's land mass is rural

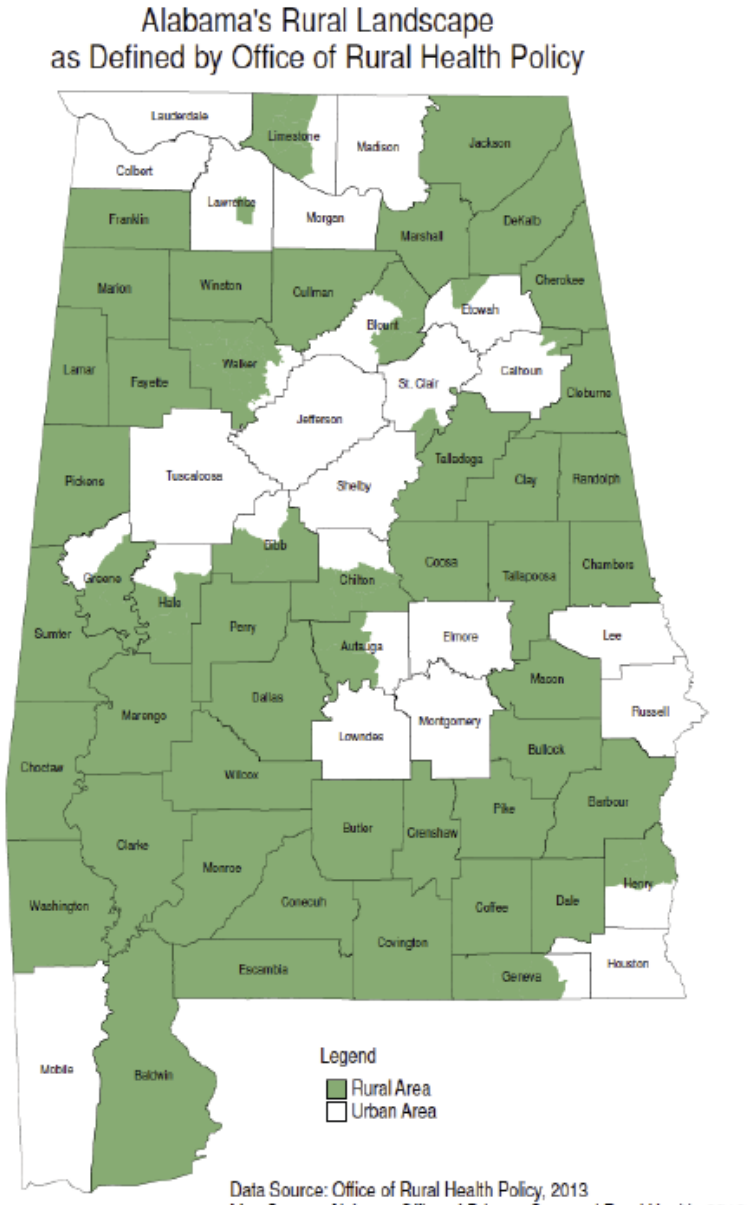
53

out of 67 Alabama counties are rural

40%

of Alabamians live in rural areas

ALABAMA CASE STUDY



Data Source: Office of Rural Health Policy, 2013
Map Source: Alabama Office of Primary Care and Rural Health, 2013

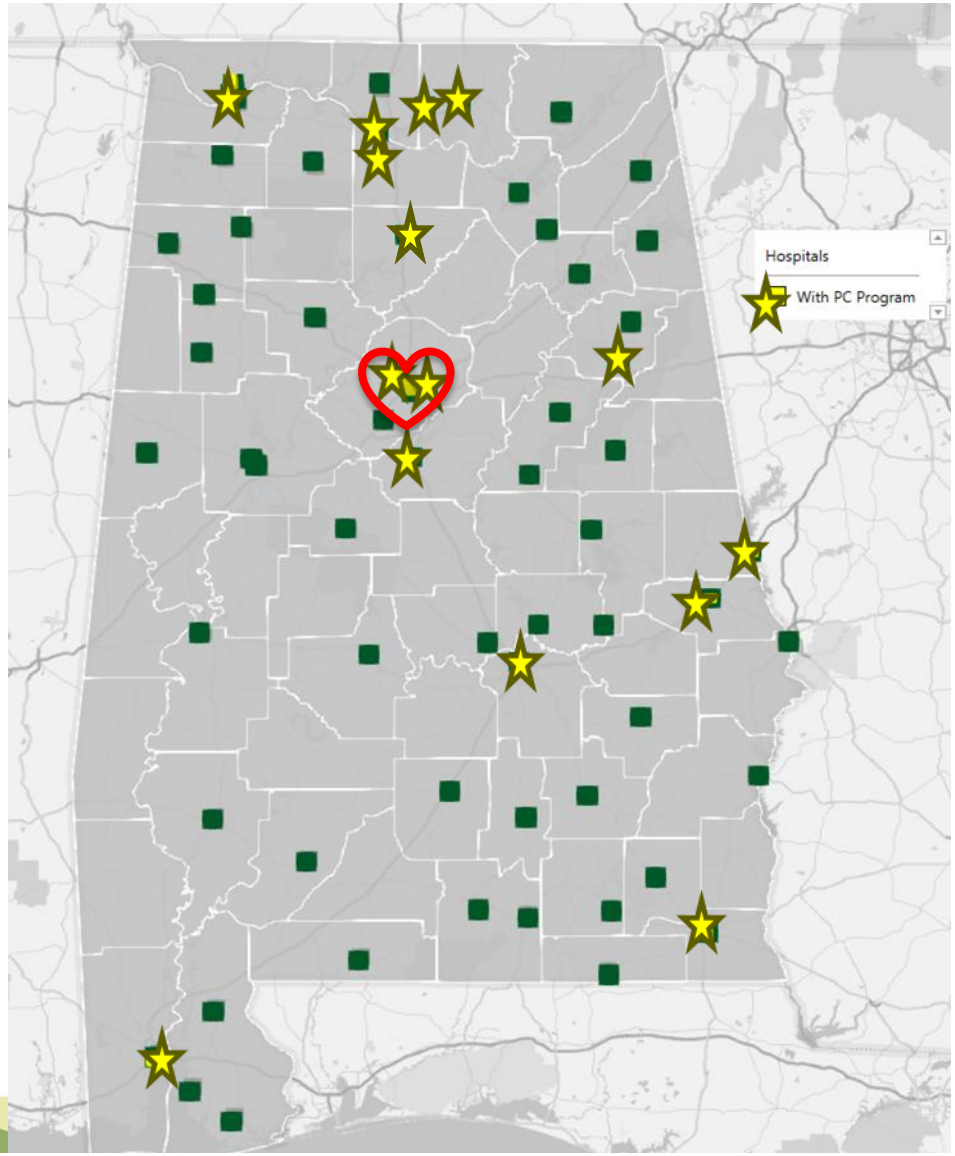
>50%

of Alabama Hospitals are in rural areas

8

counties have no hospital

Why Did Alabama Get a "D"?*



32% (16/50)

of hospitals report palliative services

50% (8/16) public

46% (7/16) not-for-profit

4% (1/16) for profit

14

counties have no hospice services

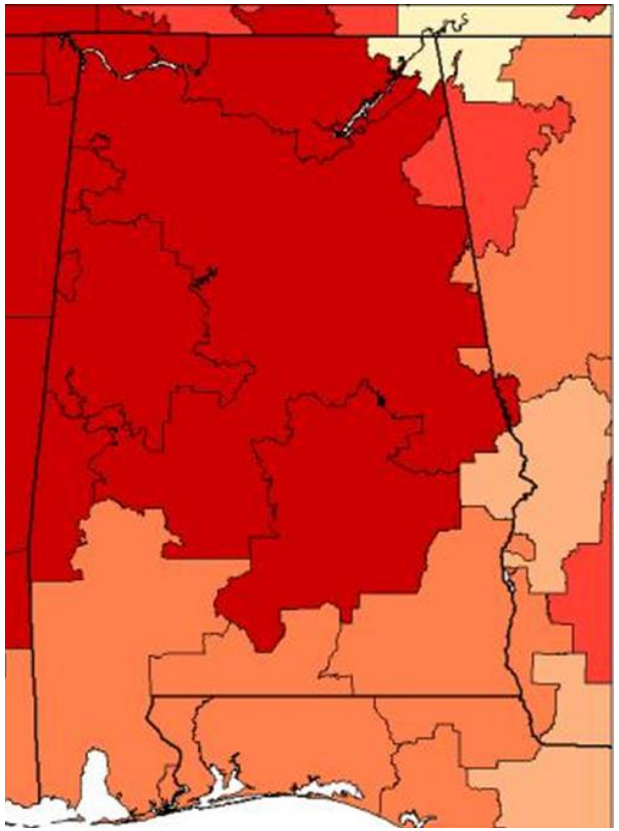
ALABAMA HOSPITALS WITH AND WITHOUT PALLIATIVE CARE SERVICES (2013)

Relationship between rural locale, palliative care expertise and suffering

Alabama's Rural Landscape
as Defined by Office of Rural Health Policy

Data Source: Office of Rural Health Policy, 2013
Map Source: Alabama Office of Primary Care and Rural Health, 20

% cancer patients dying in hospital (2003-07)



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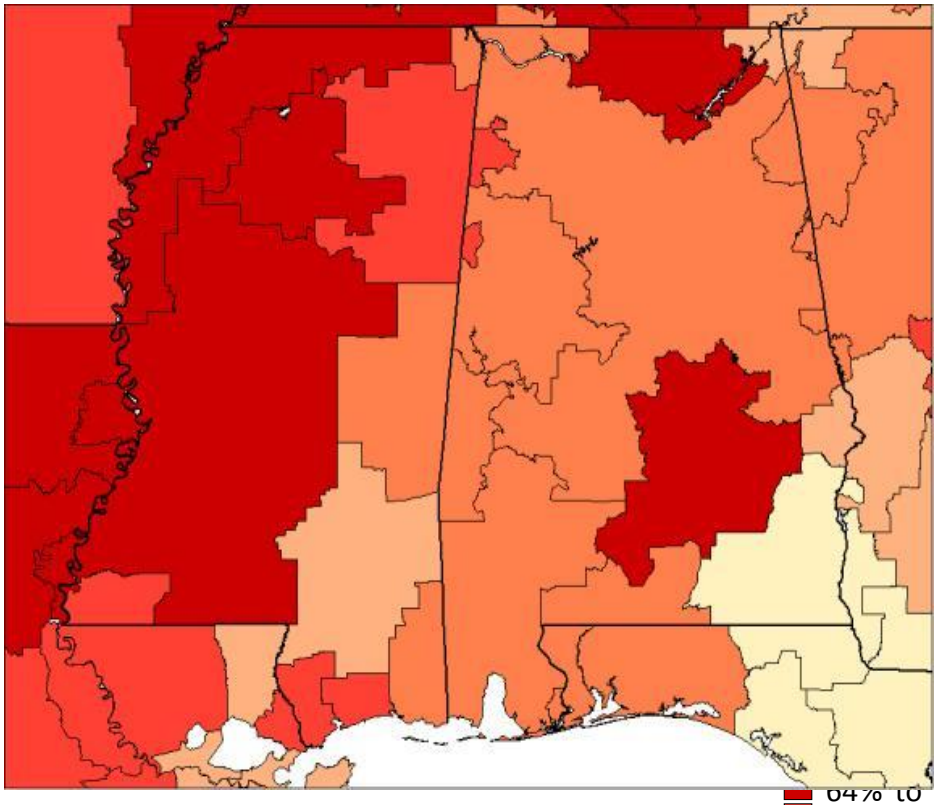
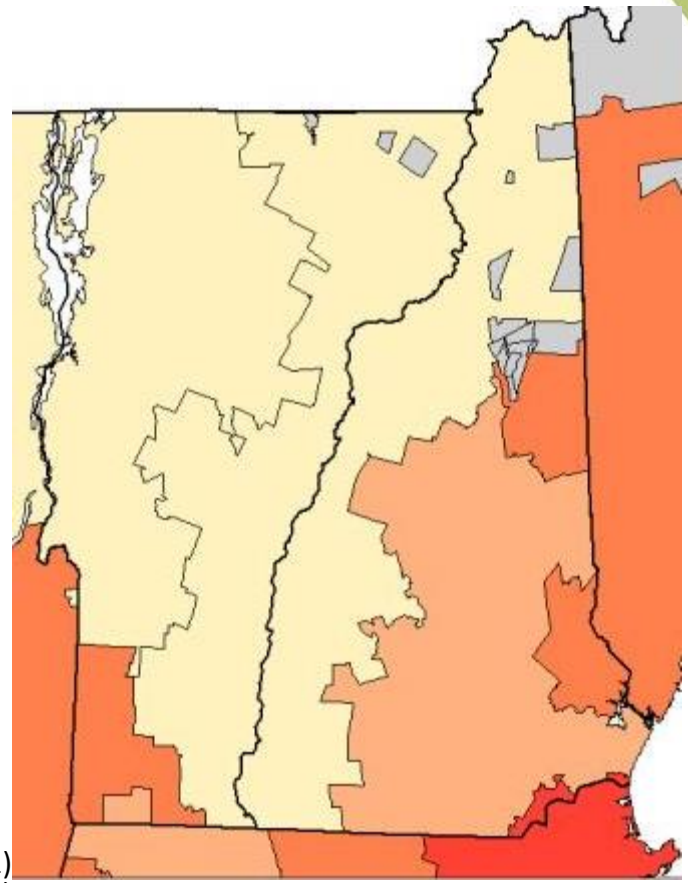
Relationship between rural locale, palliative care expertise and resource use

% cancer patients **hospitalized during last month of life** (2003-07)





64% to 71% (61)
62% to < 64% (49)
60% to < 62% (63)
57% to < 60% (66)
44% to < 57% (67)
Not populated

MI/AL

VT/NH

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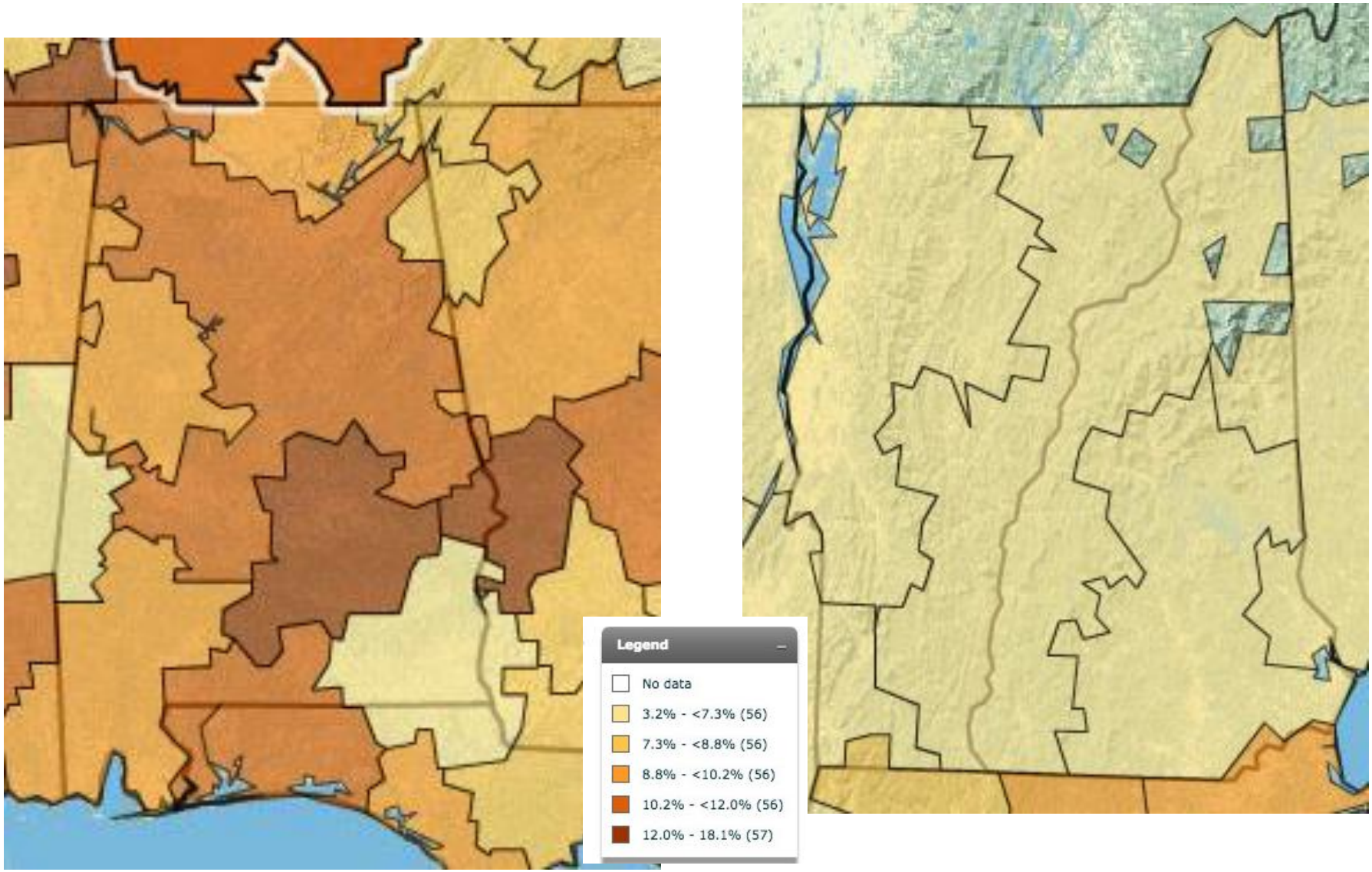
% OF CANCER PATIENTS RECEIVING LIFE SUSTAINING PROCEDURES DURING THE LAST MONTH OF LIFE
(Year: 2012; Region Level: HRR)



Overcoming Barriers to Palliative Care EVERYWHERE

- Raise awareness that palliative care encompasses more than end-of-life care
- Discover & disseminate scalable models
  - Non-inpatient/ICU community & rural settings
  - Patients with non-cancer diseases & family caregivers
- Address palliative care workforce
  - Increase specialists
  - Educate generalists

Outline

I. Palliative Care in Low Resource Areas: Unique Access Challenges

II. Innovative Models/Strategies for Achieving Palliative Care Everywhere

-telehealth
-community lay navigators

Project ENABLE

Educate, ***N***urture, ***A***dvise, ***B***efore ***L***ife ***E***nds

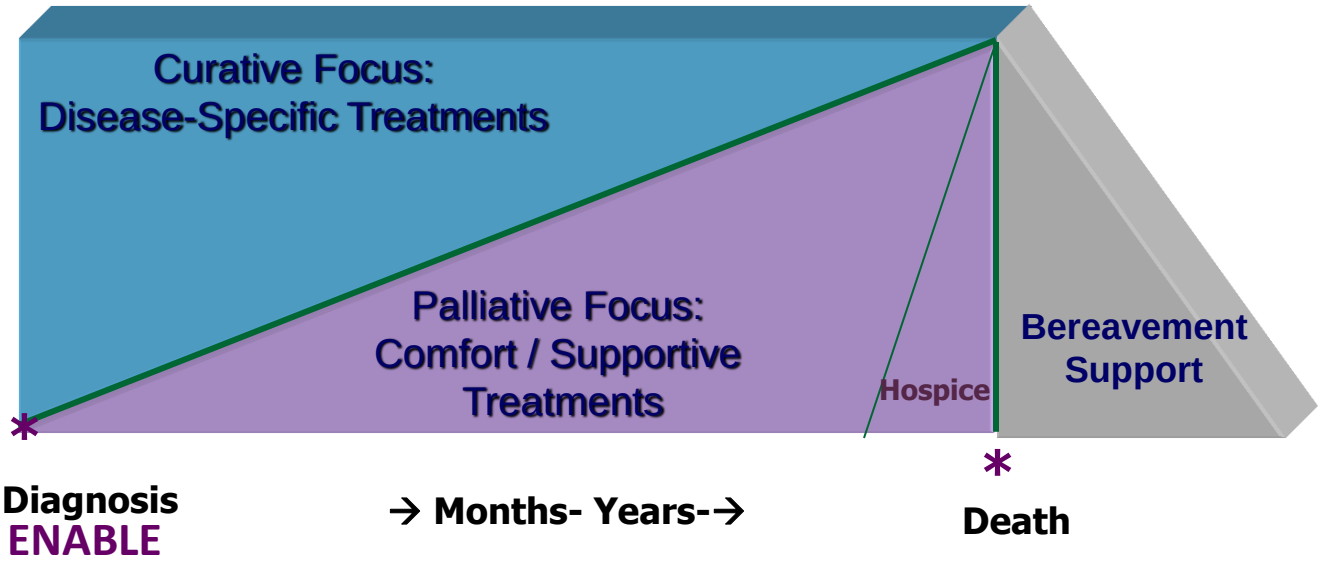
Goal: Determine a feasible model and to introduce palliative/hospice principles at the time of new advanced cancer diagnosis (as recommended by the World Health Organization).

Funded by: The Robert Wood Johnson Foundation

Norris Cotton Cancer Center at Dartmouth Hitchcock Medical Center & Visiting Nurse/Hospice of Vermont and New Hampshire

Project ENABLE

***E**ducate, **N**urture, **A**dvise, **B**efore **L**ife **E**nds*



Education & F/U >>>>>>>>>>>>>>>>>>>>>>>>>>>till death & caregiver bereavement

***Adapted from World Health Organization 1990**

ENABLE I (1999-2001; in person)

- **"Charting Your Course"- 4 structured sessions by a palliative care nurse**
  - Problem-solving/Behavioral Activation/ Empowerment
  - Symptom Management
  - Support and Communication
  - Advance Care Planning, loss, grief
- **Monthly Follow up, care coordination, referral**
- **Family bereavement immediate and 3 month evaluation**

Palliative and Supportive Care (2009), **7**, 75–86. Printed in the USA.

doi:10.1017/S1478951509000108

The project ENABLE II randomized controlled trial to improve palliative care for rural patients with advanced cancer: Baseline findings, methodological challenges, and solutions

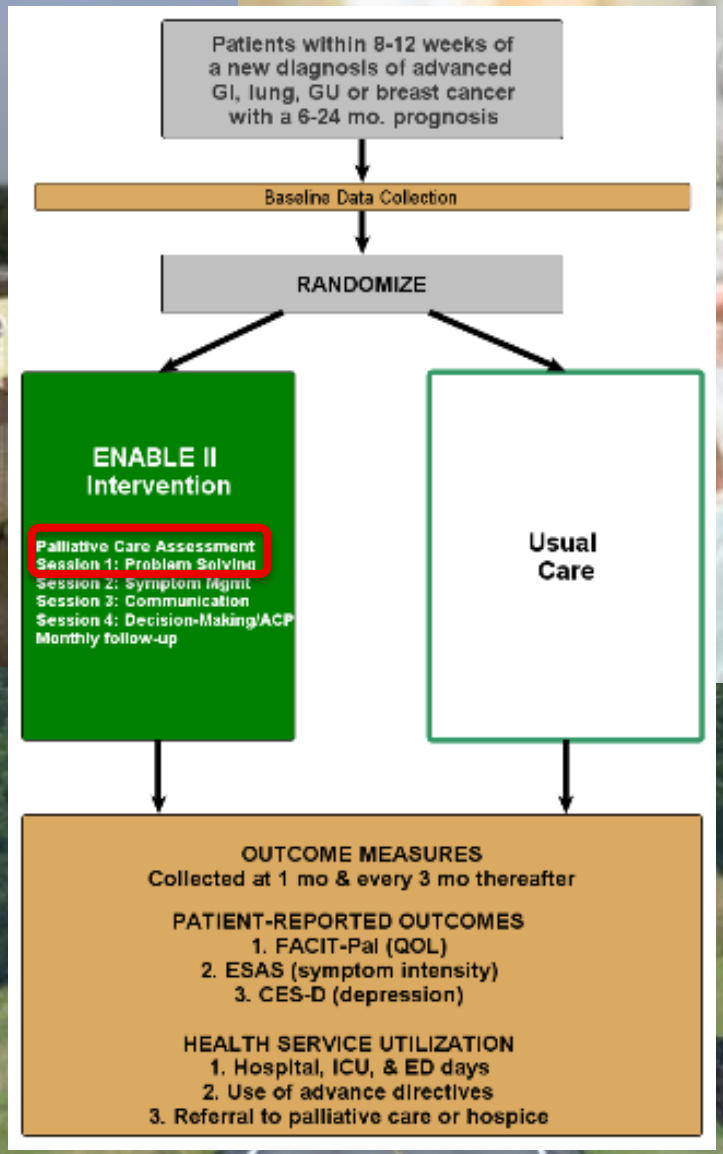
MARIE BAKITAS, D.N.SC., A.R.N.P., F.A.A.N.,[1,2,3] KATHLEEN DOYLE LYONS, SC.D., O.T.R.,[4] MARK T. HEGEL, PH.D.,[4] STEFAN BALAN, M.D.,[5] KATHLEEN N. BARNETT, M.A., A.P.R.N., B.C.-P.C.M.,[4] FRANCES C. BROKAW, M.D., M.S.,[2,6] IRA R. BYOCK, M.D.,[1,2] JAY G. HULL, PH.D.,[7] ZHONGZE LI, M.S.,[8] ELIZABETH MCKINSTRY, M.S.,[4] JANETTE L. SEVILLE, PH.D.,[4] AND TIM A. AHLES, PH.D.[9]

[1]Department of Anesthesiology, Dartmouth Medical School, Hanover, New Hampshire
[2]Section of Palliative Medicine, Dartmouth-Hitchcock Medical Center, Lebanon, New Hampshire
[3]School of Nursing, Yale University, New Haven, Connecticut
[4]Department of Psychiatry, Dartmouth Medical School, Hanover, New Hampshire
[5]White River Junction, Veterans Administration Medical Center, White River Junction, Vermont
[6]Department of Medicine, Dartmouth Medical School, Hanover, New Hampshire, USA
[7]Dartmouth College, Hanover, New Hampshire
[8]Biostatistics Shared Resource, Norris Cotton Cancer Center, Dartmouth College, Hanover, New Hampshire
[9]Department of Psychiatry, Memorial Sloan-Kettering Cancer Center, New York, New York

(RECEIVED July 25, 2008; ACCEPTED October 10, 2008)

ENABLE II (2003-2007) – Phone-based

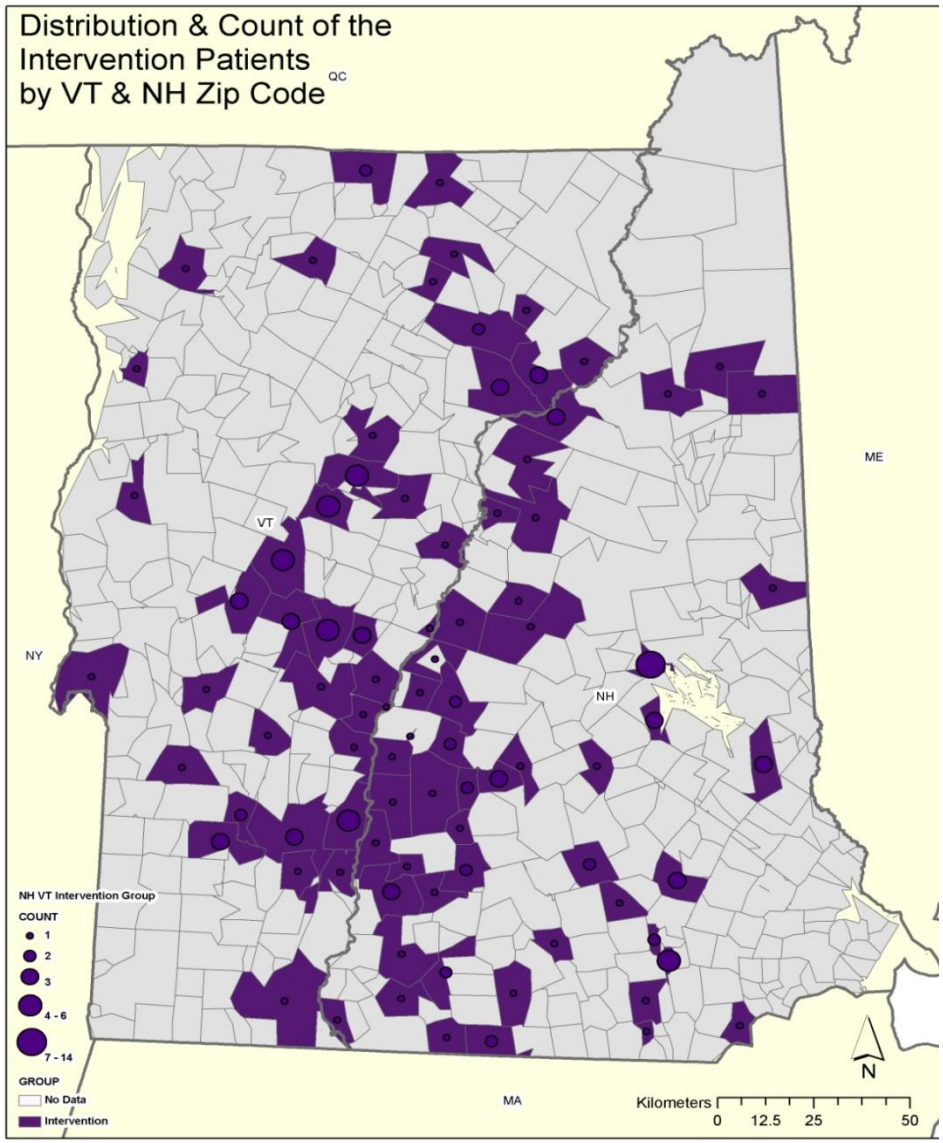
STUDY SCHEMA

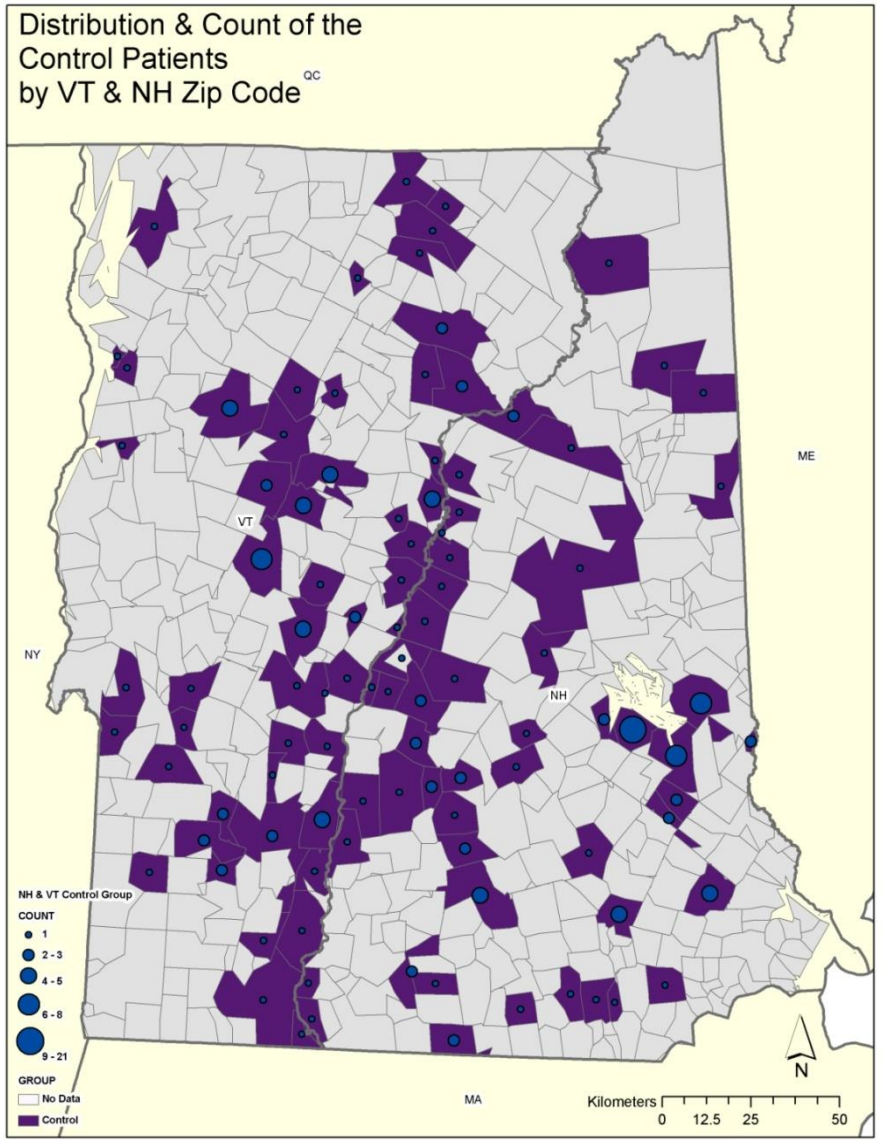


Growing Use of Telehealth

"We now feel it's cheaper to do surgery via Skype. So, go home and lie down in front of your computer."

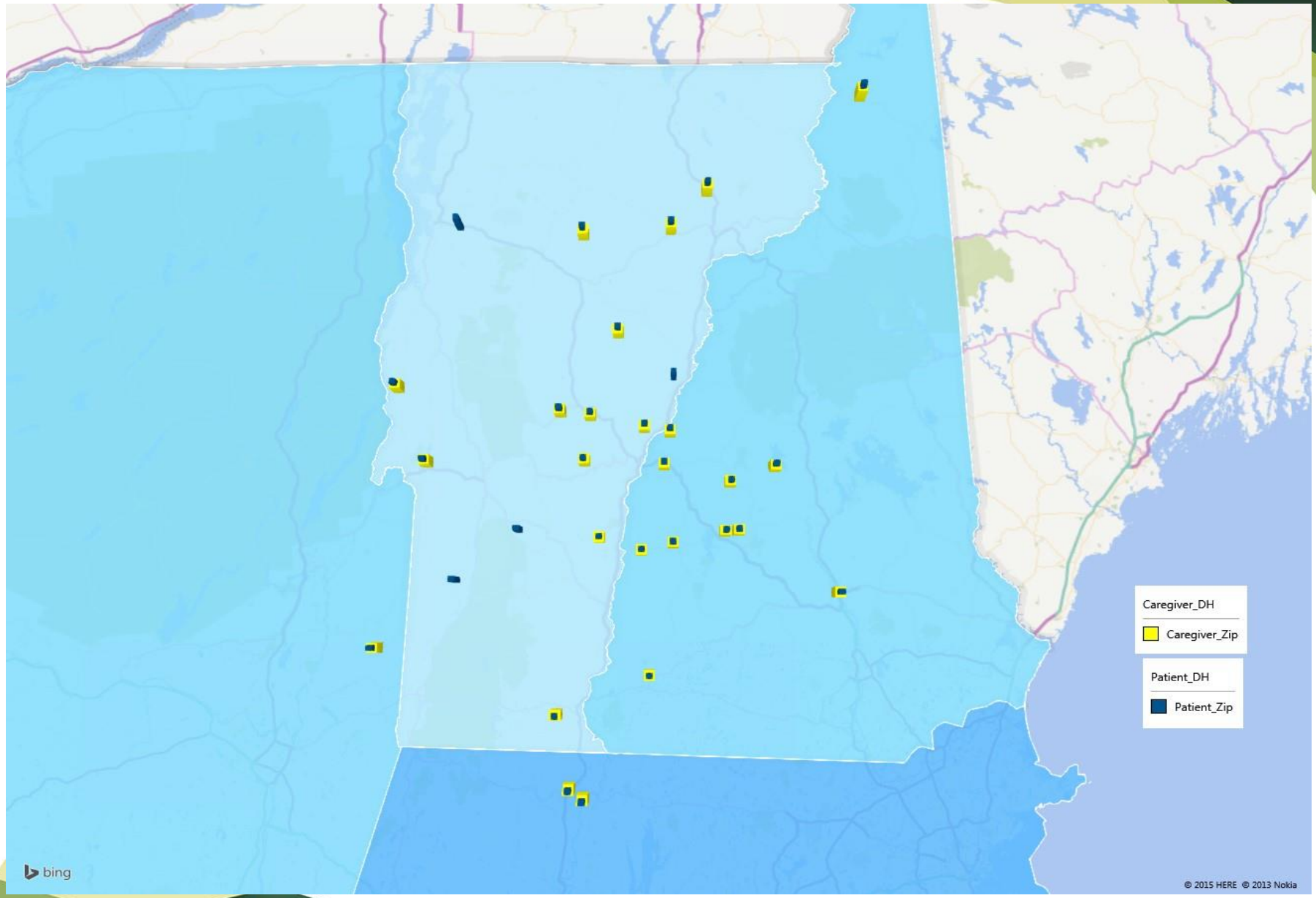
Distribution & Count of ENABLE II Intervention & Control Patients



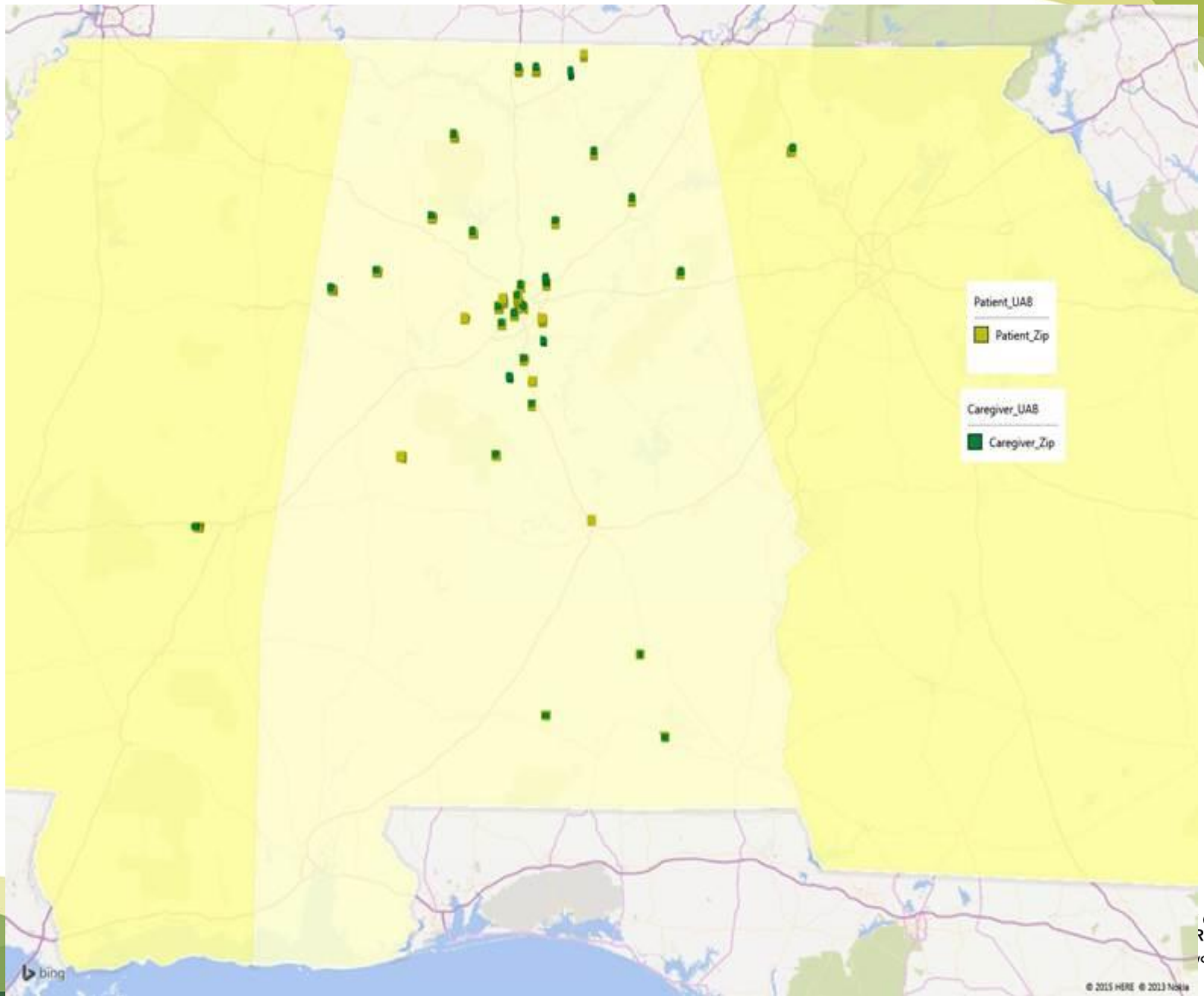


2009 Courtesy of Jennifer Alford-Teaster, GIS/Spatial Analysis Specialist, Department of Geography, Dartmouth College

Geographic Distribution of ENABLE HF Pilot PT-CG Participants-DH



Geographic Distribution of ENABLE HF Pilot PT-CG Participants-UAB



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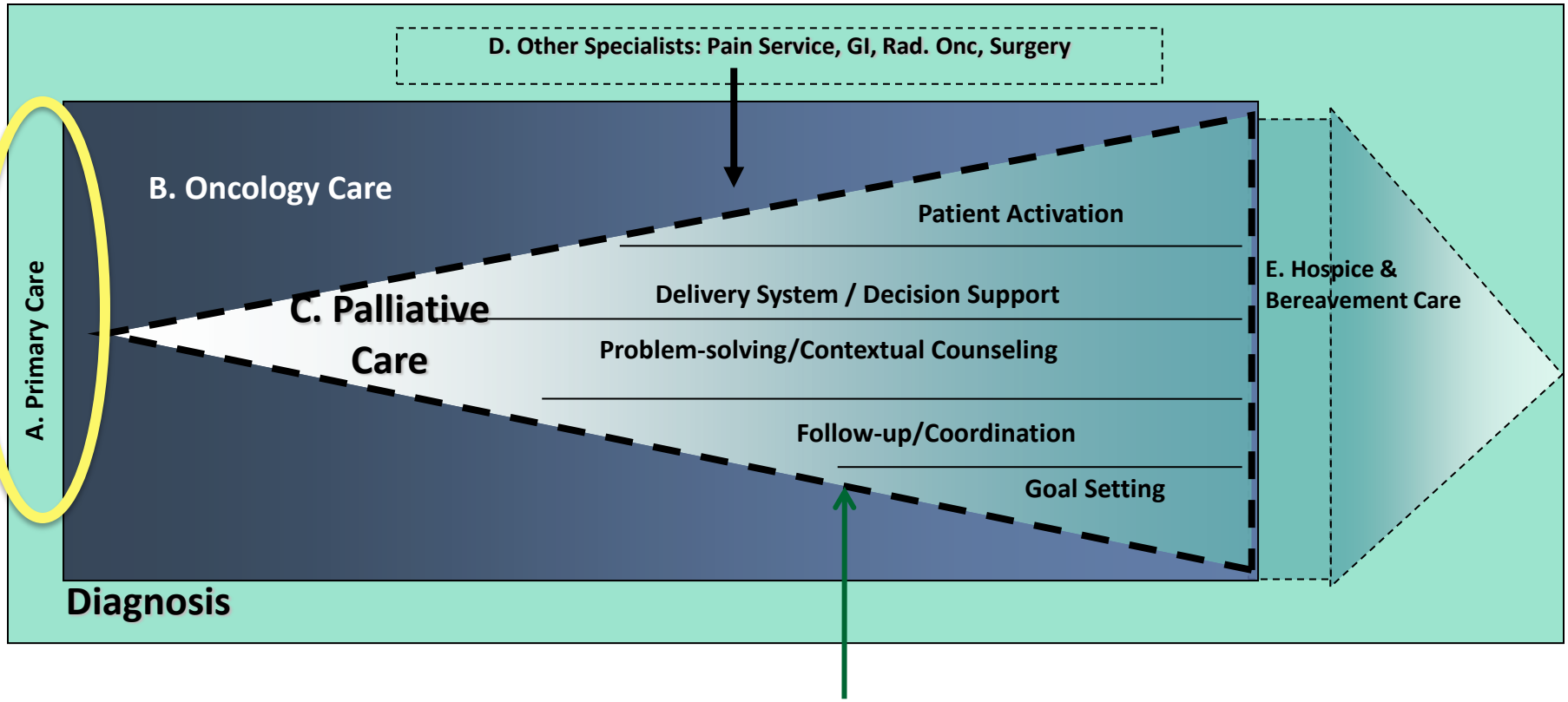
Community Primary Care Providers: An ENABLE Essential Element!



Effects of a Palliative Care Intervention on Clinical Outcomes in Patients With Advanced Cancer

The Project ENABLE II Randomized Controlled Trial

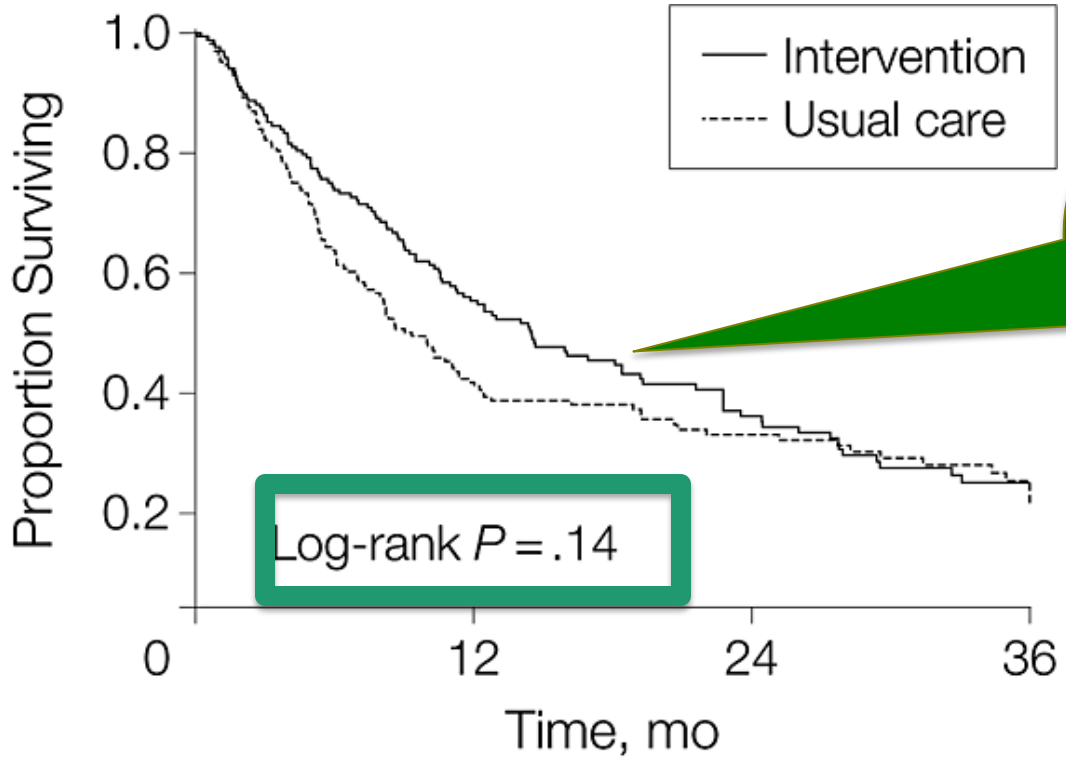
Marie Bakitas, DNSc, APRN
Kathleen Doyle Lyons, ScD, OTR
Mark T. Hegel, PhD
Stefan Balan, MD
Frances C. Brokaw, MD, MS
Janette Seville, PhD
Jay G. Hull, PhD
Zhongze Li, MS
Tor D. Tosteson, ScD
Ira R. Byock, MD
Tim A. Ahles, PhD

- First study to demonstrate EPC improves **QOL (*P*=0.02)** & **mood (*P*=0.02)**
- Trend toward improved symptom intensity (*P*=0.06)…

2009;302:741-749 JAMA

Effects of a Palliative Care Intervention on Clinical Outcomes in Patients With Advanced Cancer

The Project ENABLE II Randomized Controlled Trial



Median survival
8.5 mo vs. 14 mo.
5.5 mo > survival

No. at risk				
Intervention	161	83	35	16
Usual care	161	62	33	16

JAMA
2009;302:741-749

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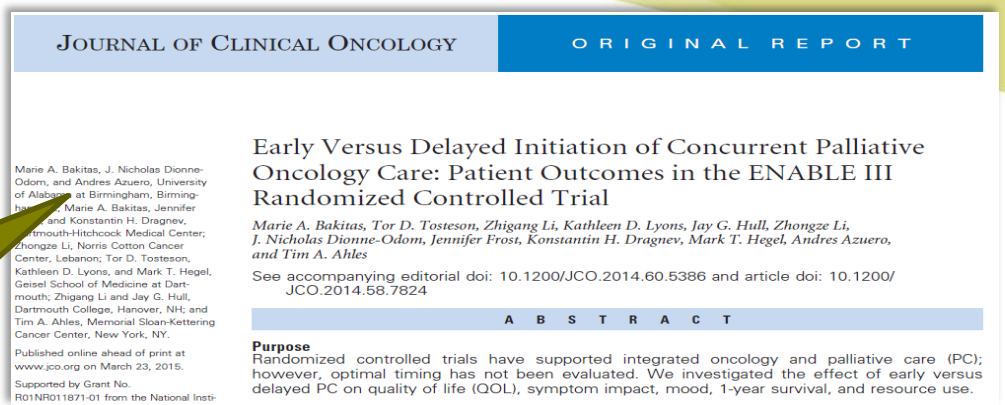
No difference in PROs



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

See accompanying editorial doi: 10.1200/JCO.2014.60.5386 and article doi: 10.1200/JCO.2014.58.7824

ABSTRACT

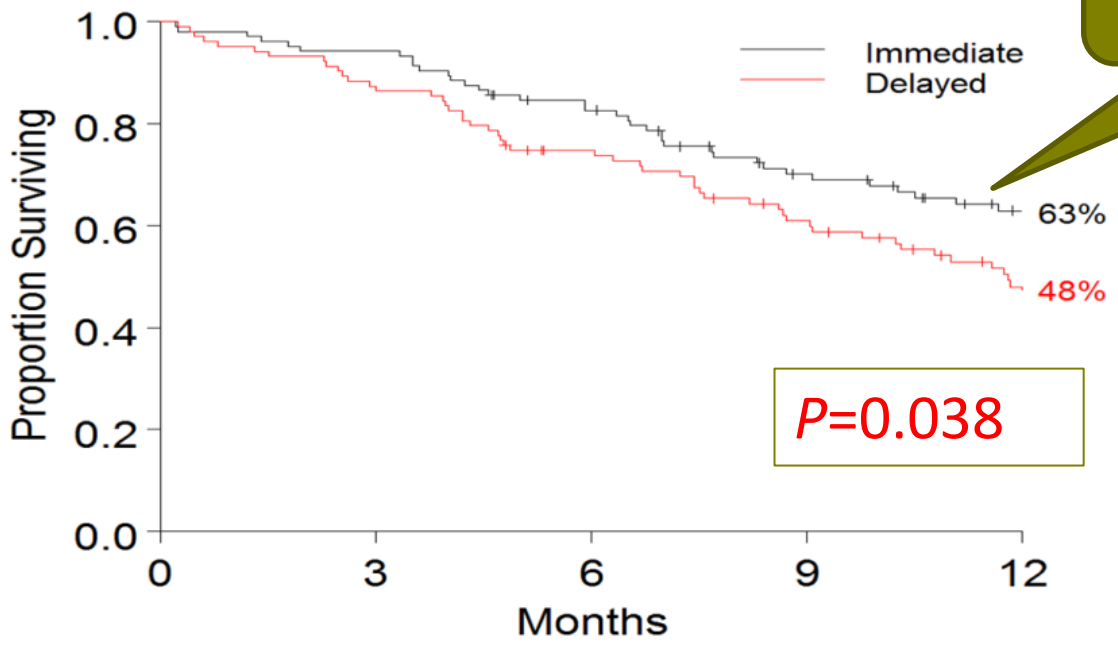
Purpose
Randomized controlled trials have supported integrated oncology and palliative care (PC); however, optimal timing has not been evaluated. We investigated the effect of early versus delayed PC on quality of life (QOL), symptom impact, mood, 1-year survival, and resource use.

Marie A. Bakitas, J. Nicholas Dionne-Odom, and Andres Azuero, University of Alabama at Birmingham, Birmingham; Marie A. Bakitas, Jennifer [illegible] and Konstantin H. Dragnev, [illegible]rtmouth-Hitchcock Medical Center; Zhongze Li, Norris Cotton Cancer Center, Lebanon; Tor D. Tosteson, Kathleen D. Lyons, and Mark T. Hegel, Geisel School of Medicine at Dartmouth; Zhigang Li and Jay G. Hull, Dartmouth College, Hanover, NH; and Tim A. Ahles, Memorial Sloan-Kettering Cancer Center, New York, NY.

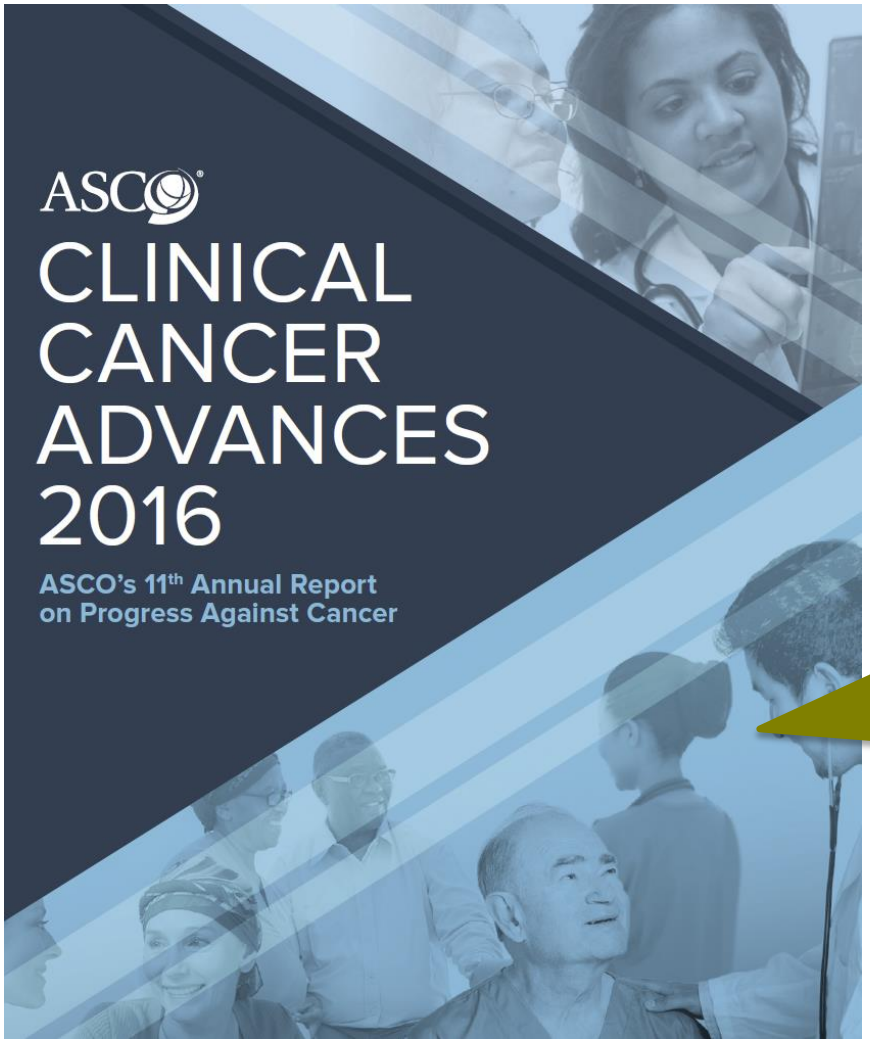
Published online ahead of print at www.jco.org on March 23, 2015.

Supported by Grant No. R01NR011871-01 from the National Insti-

Early PTs had ↑1 yr. survival



No. at Risk					
Immediate	104	98	83	62	48
Delayed	103	89	73	55	39



PALLIATIVE CARE BENEFITS EXTEND BEYOND THE PATIENT

ENABLE III for patients and caregivers featured as one of the year's major achievements in clinical cancer research and care.

Center for Medicare & Medicaid Innovation:
Grant Number 1C1CMS331023

UAB Patient Care Connect

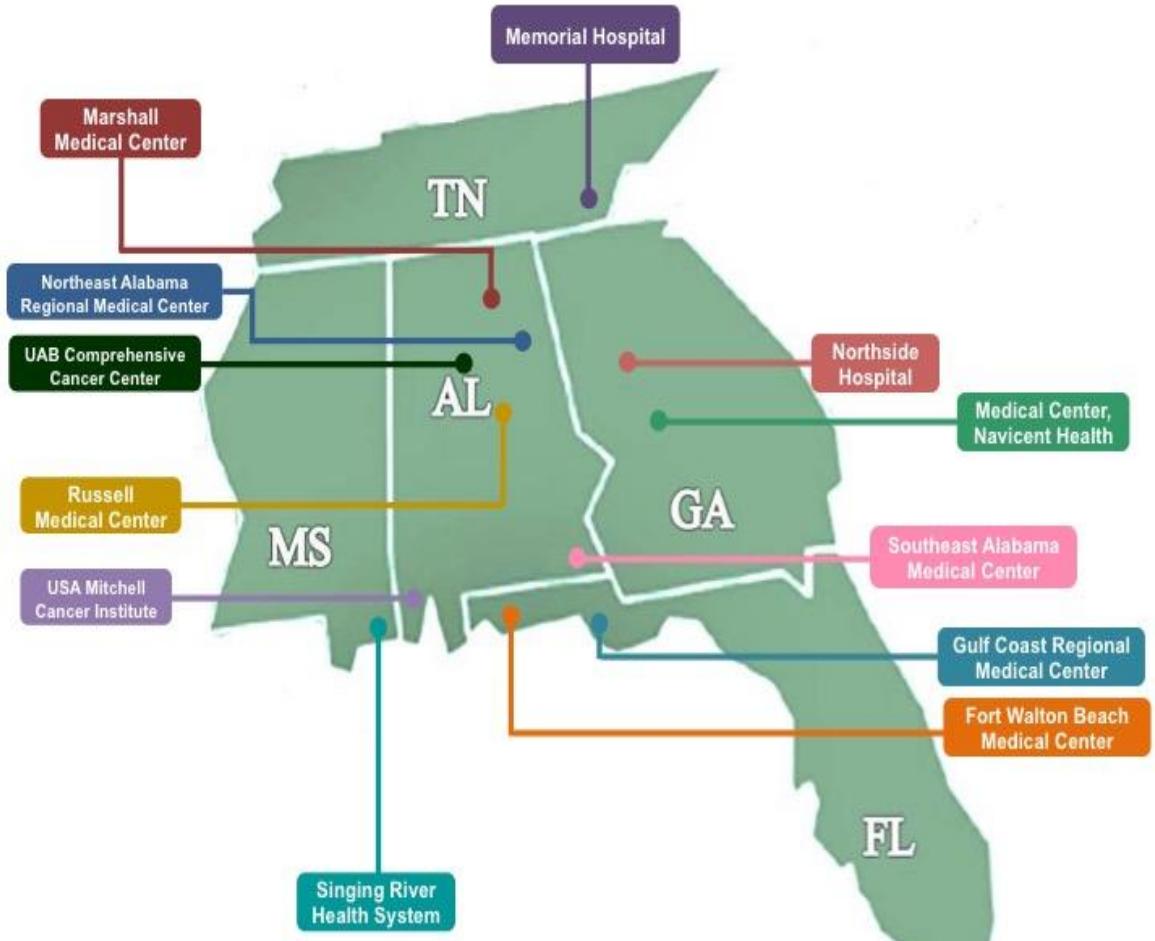
- **Ed Partridge, MD (Principal Investigator)**
- Gabrielle Rocque, MD
- Maria Pisu, PhD
- Elizabeth Kvale, MD
- **Wendy Demark-Wahnefried, PhD, RD**
- **Karen Meneses, PhD, RN**
- Michelle Martin, PhD
- Mona Fouad, MD, MPH
- Bradford Jackson, PhD
- Yufeng Li, PhD
- Kelly Kenzik, PhD
- Terri Salter, RN, MSN, MBA
- Richard Taylor, DPN,CRNP
- Aras Acemgil, MBA
- Nedra Lisovicz, PhD, MPH
- Carol Chambless
- Valeria Pacheco-Rubi

Special thank you to our patients, caregivers, navigators, and UAB Health System Cancer Community Network Partners

Patient Care Connect Program

University of Alabama at Birmingham Health System
Cancer Community Network (CCN)

- 12 cancer centers across 5 southeastern states
- ~40 lay navigators (non-clinical)
- Nurse site managers



PATIENT CARE CONNECT
A service of UAB Health System Cancer Community Network

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Knowledge that will change your world

Target Population

1. Medicare-Primary A and/or B

2. Age ≥ 65

3.Cancer Diagnosis
   - Patients with high risk disease and/or psychosocial complexity

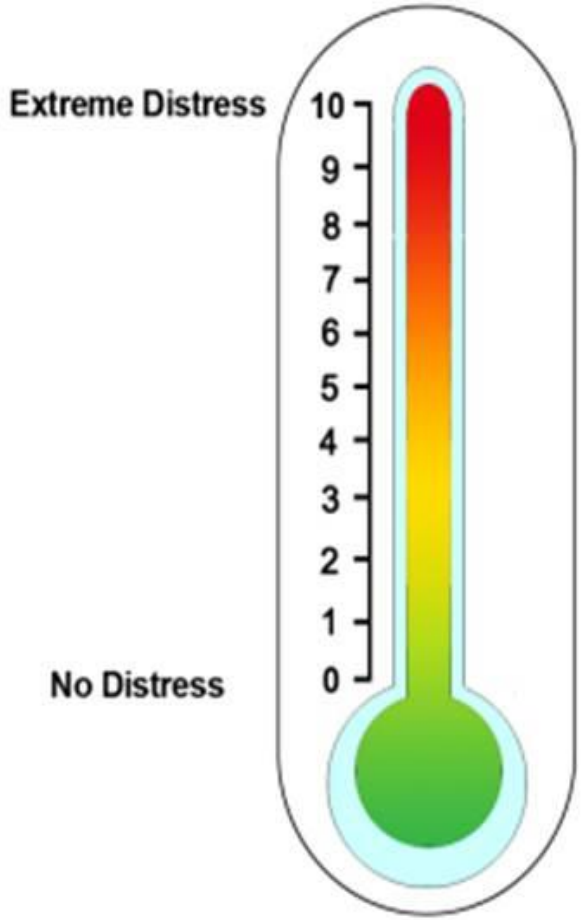
Lay Navigators
Patient Care Connect Program

- Goal of improving **VALUE**
- Provides extra layer of support to cancer patients across the continuum of care
- Activities anchored by distress screening

Lay Navigators Extend the Reach of Palliative Care

Distress Thermometer

- Screen the level of distress
- Guides Interview/conversation
- Allows early, PROACTIVE detection and intervention
- Drives patient focused care planning
  - professional referral
  - interventions



Who are lay navigators?

- Established members of the community they serve
- “natural helpers”

- Recruited by sites: “who in the community would you expect to have helpful guidance if…”

- Retired school teachers, cancer survivors, persons who had some medical exposure (worked desk at local MD office…)

What do Lay Navigators Do?

- **EMPOWER** patients to take an active role in their healthcare
  - Identify resources
  - Recognize clinical symptoms
  - Understand disease and treatment
  - Engage in ACP/end-of-life discussions with their providers

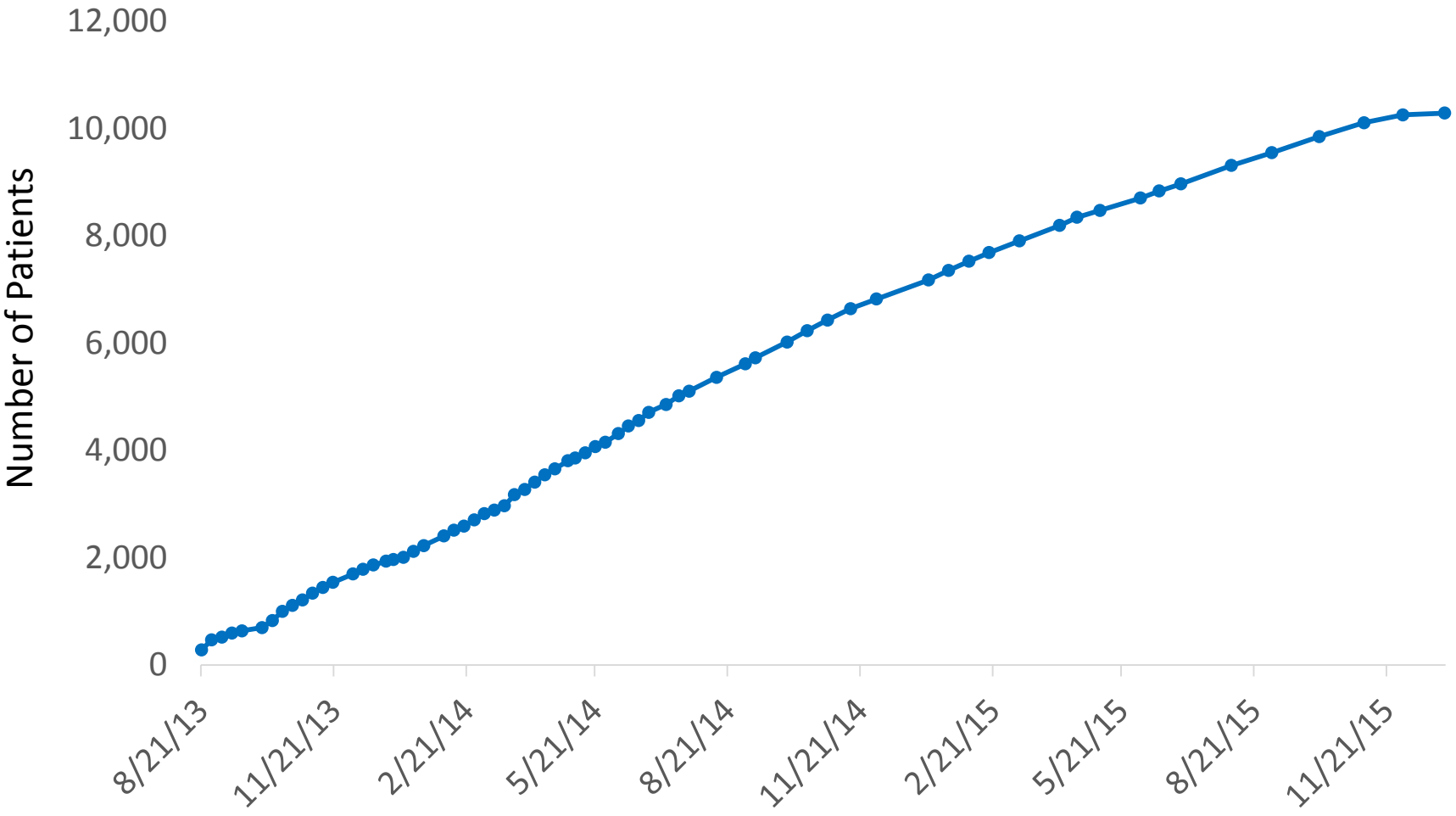
- **Eliminate Barriers**
  - Link patients with resources to get to appointments
  - Connect patients to providers to address symptoms
  - Coordinate care between multiple providers

- **Ensure Timely Delivery of Care**
  - Help patients navigate the health care system
  - Assist with access to care

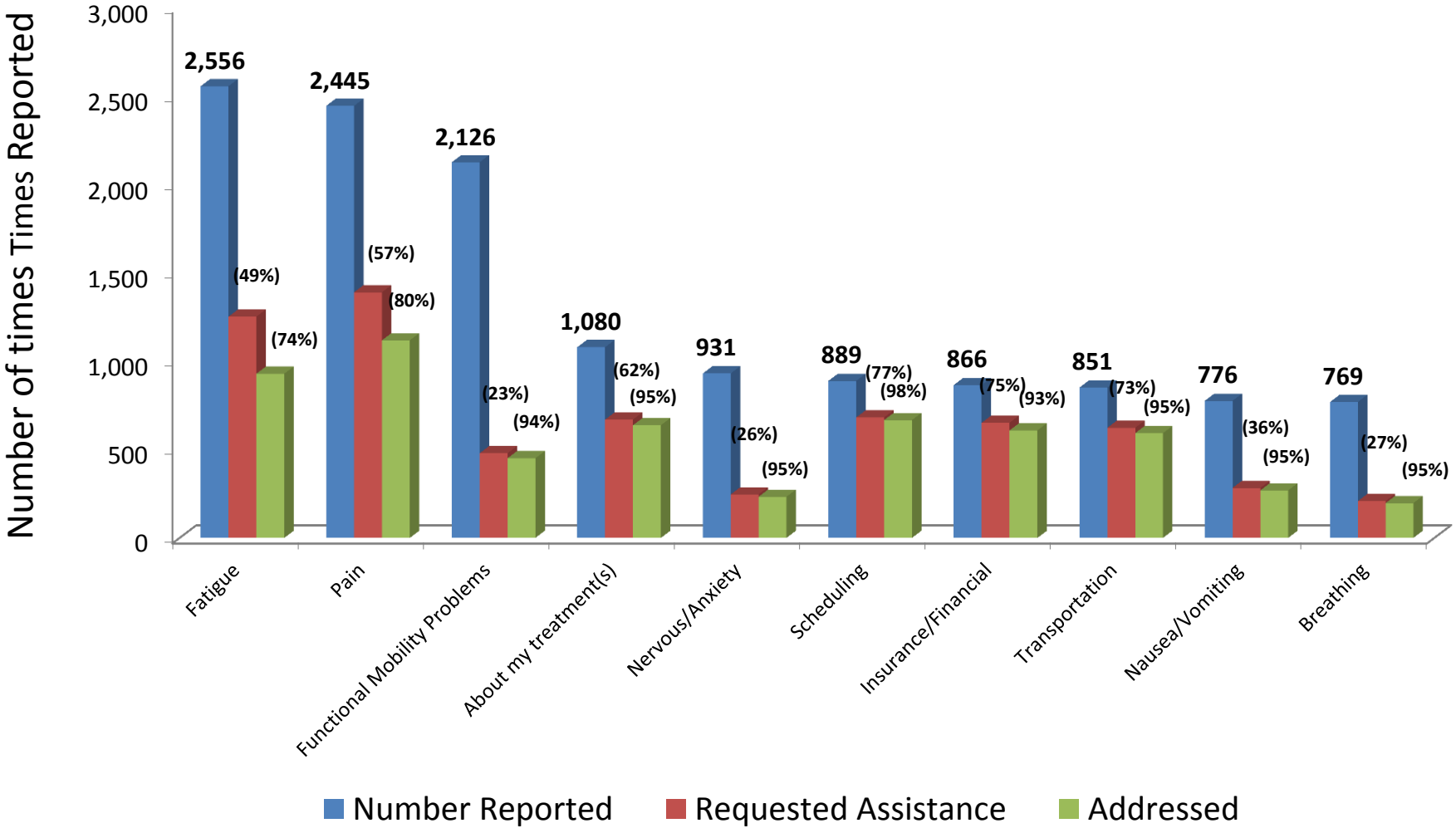
How are Lay Navigators Trained?

- 5 days face-to-face training & team building sessions
- Curriculum:
  - Communication – motivational interviewing
  - Cancer basics
  - Advanced cancer
  - Symptom burden
  - Navigator role and responsibilities
  - Boundaries
  - Advance care planning-”Respecting Choices”

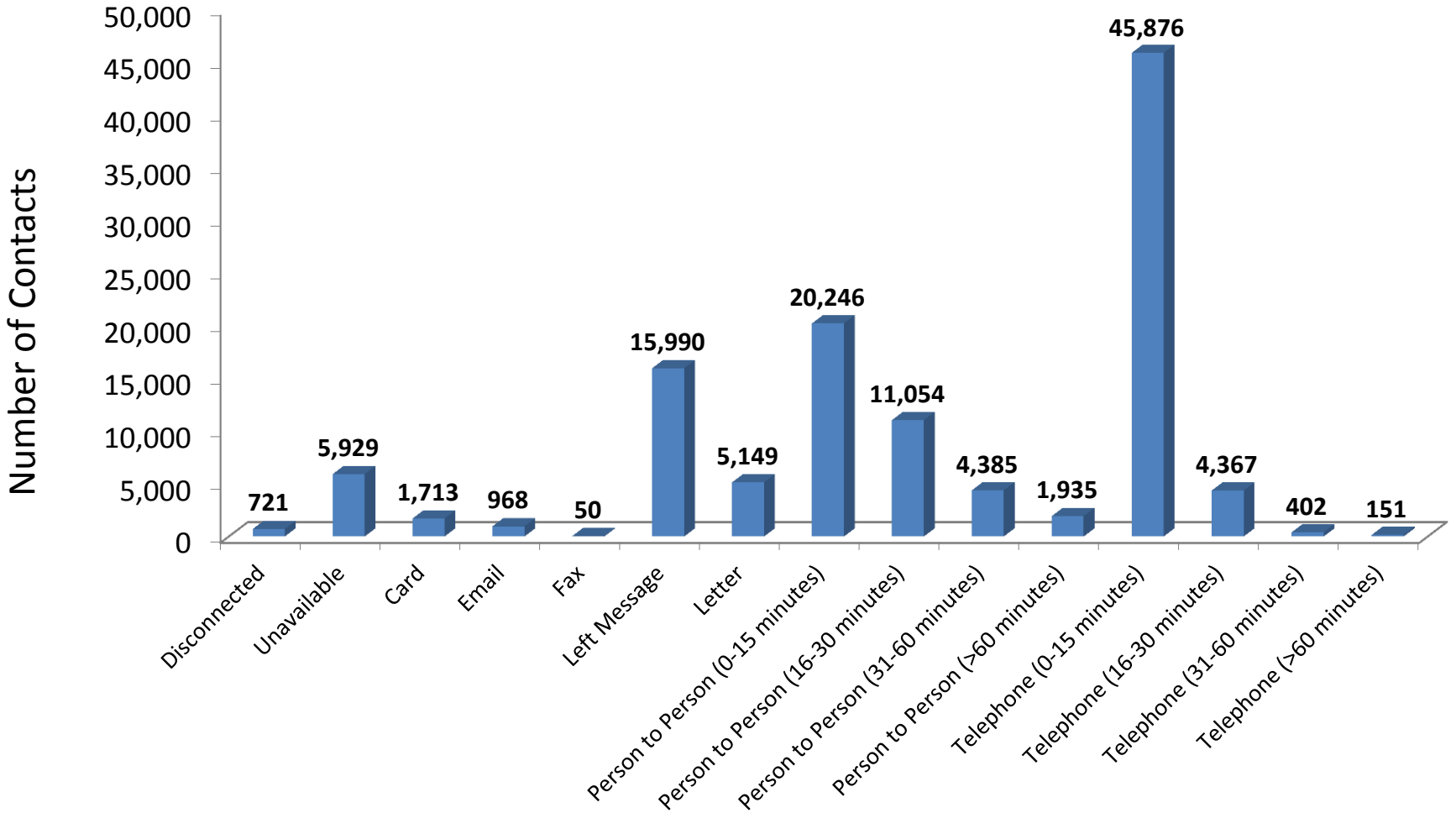
Enrollment In Navigation



Distress Screening



PCC Patient Contacts (3/2013-12/2016)



Preliminary Results of Navigation vs Usual Care

- > 10,000 Medicare beneficiaries enrolled in program

↑ Hospice enrollment

↓ ER, hospitalizations, and ICU admissions

↓ decrease in cost

↑ patient satisfaction

The Challenge…

JOURNAL OF CLINICAL ONCOLOGY

ASCO SPECIAL ARTICLE

Integration of Palliative Care Into Standard Oncology Care: American Society of Clinical Oncology Clinical Practice Guideline Update

Betty R. Ferrell, Jennifer S. Temel, Sarah Temin, Erin R. Alesi, Tracy A. Balboni, Ethan M. Basch, Janice I. Firn, Judith A. Paice, Jeffrey M. Peppercorn, Tanyanika Phillips, Ellen L. Stovall,† Camilla Zimmermann, and Thomas J. Smith

Betty R. Ferrell, City of Hope Medical Center, Duarte, CA; Jennifer S. Temel and Jeffrey M. Peppercorn, Massachusetts General Hospital; Tracy A. Balboni, Dana-Farber Cancer Institute, Boston, MA; Sarah Temin, American Society of Clinical Oncology, Alexandria, VA; Erin R. Alesi, Janice I. Firn, Judith A. Paice, Tanyanika Phillips, Ellen L. Stovall, and Jeffrey Peppercorn, Northwestern University, Chicago; Ethan M. Basch, University of North Carolina, Chapel Hill; Janice I. Firn, Providence Cancer Institute, Portland; Judith A. Paice, Northwestern University, Chicago, IL; Tanyanika Phillips, Ellen L. Stovall, and Camilla Zimmermann, Princess Margaret Cancer Centre, Toronto, Ontario, Canada.

†Deceased.

Published online ahead of print at www.jco.org on October 31, 2016.

Clinical Practice Guideline Committee approved: August 15, 2016.

Editor's note: This American Society of Clinical Oncology clinical practice guideline provides recommendations, with comprehensive review and analyses of the relevant literature for each recommendation. Additional information, including a Data Supplement with additional evidence tables, a Methodology Supplement, slide sets, clinical tools and resources, and links to patient information

develop an update. The 2012 PCO was based on a review of a randomized controlled trial (RCT) by the National Cancer Institute Physicians Data Query and additional trials. The panel conducted an updated systematic review seeking randomized clinical trials, systematic reviews, and meta-analyses, as well as secondary analyses of RCTs in the 2012 PCO, published from March 2010 to January 2016.

Results

The guideline update reflects changes in evidence since the previous guideline. Nine RCTs, one quasiexperimental trial, and five secondary analyses from RCTs in the 2012 PCO on providing palliative care services to patients with cancer and/or their caregivers, including family caregivers, were found to inform the update.

Recommendations

Inpatients and outpatients with advanced cancer should receive dedicated palliative care services, early in the disease course, concurrent with active treatment. Referral of patients to interdisciplinary palliative care teams is optimal, and services may complement existing programs. Providers may refer family and friend caregivers of patients with early or advanced cancer to palliative care services.

Recommendations

Inpatients and outpatients with advanced cancer should receive dedicated palliative care services, early in the disease course, concurrent with active treatment. Referral of patients to interdisciplinary

Does the Workforce Exist to Meet the Challenge?

- Who can do assessments?
  - Specialists
  - Generalists

  - Inter-professional Team
    - MD
    - APRN,PA
    - RN
    - MSW
    - Chaplains
    - Rehabilitation Therapists
    - ? Lay navigators

Summary

- Early palliative care, as envisioned by the WHO, is now an evidence-based standard in oncology - but is not widespread.
- The challenge is to scale up these evidence-based principles to patients with non-cancer diseases and in under-served areas.
- Discovery, dissemination, and workforce issues must all be addressed to make Palliative Care Everywhere a reality.

Conclusions

Challenges to providing expert palliative care in low resource areas are…

- **…surmountable!!!**
- **…require a long-term commitment & innovation**
- **…worth the effort to ensure that high quality palliative care is available for ALL patients with serious illness and the people who love them.**

THANK YOU! mbakitas@uab.edu

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