Enhancing Access to Rural Palliative Care

Marie A. Bakitas, DNSc, NP-C, FAAN
Professor, Marie O'Koren Endowed Chair, Associate Director

Elizabeth Kvale, MD
Director, Ambulatory Palliative Care

Center for Palliative and Supportive Care
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Join us for upcoming CAPC webinars and office hours

- **Webinars:**
  - **Palliative Care Partnerships: Leveraging Quality of Life Resources and Activities**
    - Featured Presenter: Rebecca A. Kirch, JD
    - Tuesday, April 28, 2015 from 1:30 - 2:30 pm ET
  - **Building a Successful Palliative Home Care Program**
    - Featured Presenter: David Casarett, MD, MA
    - Tuesday, May 5, 2015 from 1:30-2:30 pm ET

- **Office Hours:**
  - **How to Use CAPC Membership with Brynn Bowman**
    - Wednesday, April 22, 2015 from 12:00pm – 1:00pm ET
  - **Pediatric Palliative Care with Sarah Friebert, MD**
    - Wednesday, April 22, 2015 from 5:00pm – 6:00pm ET
  - **Palliative Care in the Home with Donna W. Stevens, BS**
    - Thursday, April 23, 2015 from 1:00pm – 2:00pm ET
  - **Billing and RVUs with Julie Pipke, CPC**
    - Friday, April 24, 2015 from 4:00pm – 5:00pm ET
  - **Managing Team Workflow with David E. Weissman, MD, FAAHPM**
    - Monday, April 27, 2015 from 8:00am – 9:00am ET

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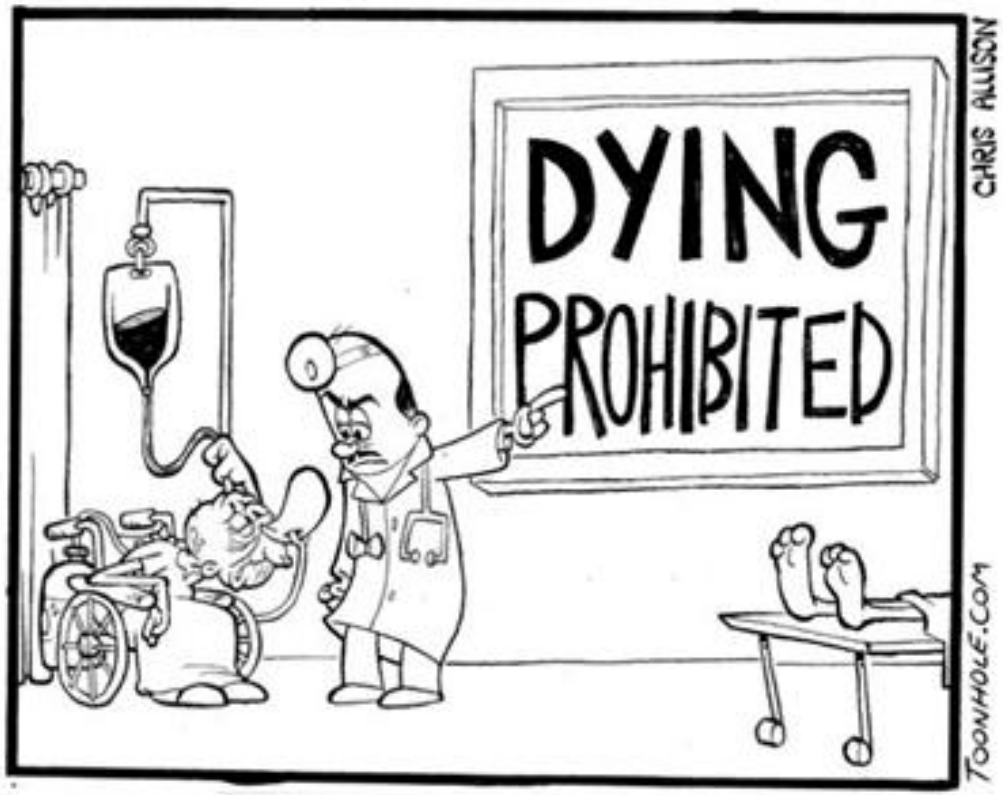
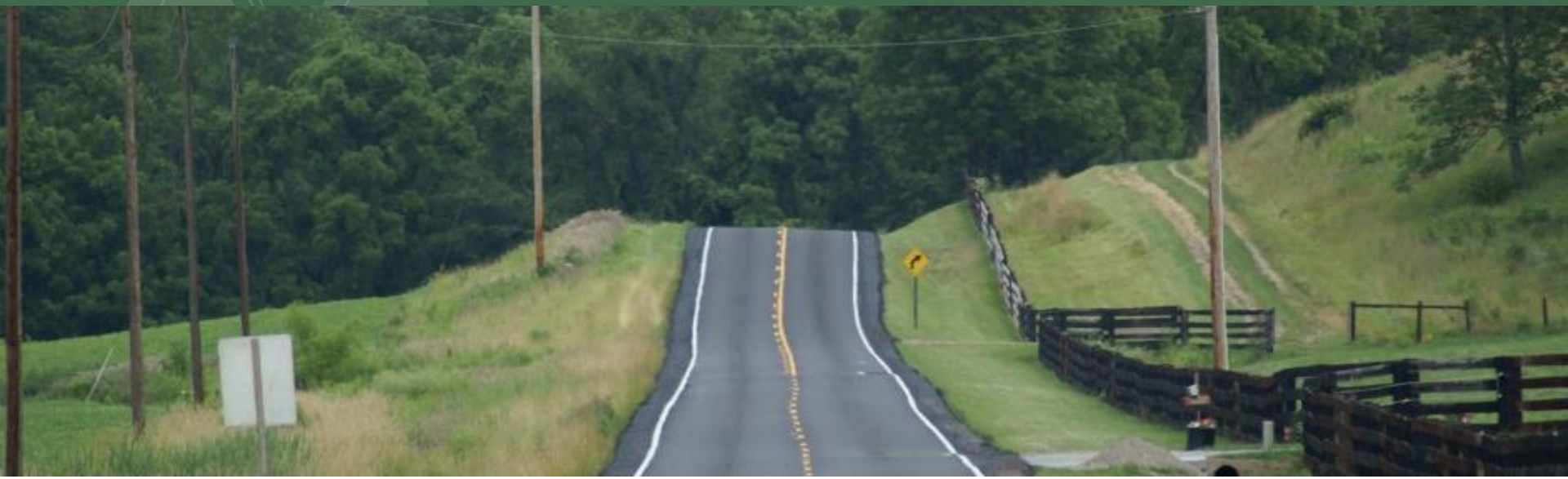
OBJECTIVES

- Recognize specific challenges and opportunities in rural palliative care development
- Delineate core palliative care skills in rural palliative care development
- Discuss 2 types of rural palliative care delivery:
  - Telehealth
  - Community health workers/Lay navigators

Problem #1: The focus of palliative care delivery has been on developing inpatient care (units) and consult services in academic, tertiary care medical centers.



Could offering palliative care upstream influence decision-making and result in fewer patients entering the hospital at end-of-life?



Problem #2: Delivering Palliative Care in Rural Areas is Different

Rural Palliative Care: What's Different?

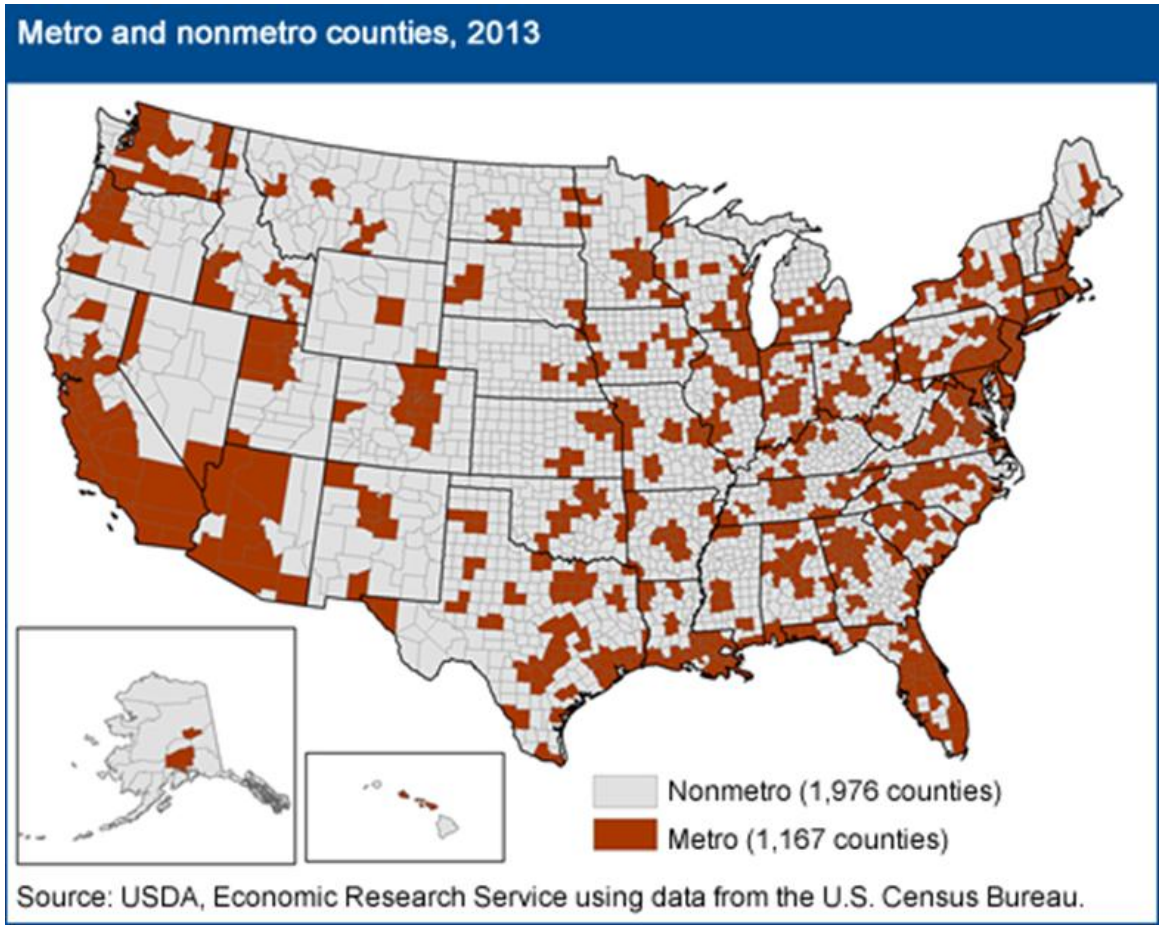
- Bertha is 78 yo French Canadian, Catholic woman with recurrent ovarian cancer, ascites, dyspnea admitted to local critical access hospital.
- Transfer to the "academic center" 90 miles away.
- Gyn Onc recommends chemo; Patient has limited English language skills accepts treatment.
- Family unable to visit.
- Bertha dies alone in hospital from neutropenic fever/sepsis.

Critical Access Hospital Criteria

- Rural, located within a state participating in the Medicare Rural Hospital Flexibility program
- More than a **35-mile drive** from any other hospital or CAH (or, in the case of mountainous terrains or in areas where only secondary roads are available, more than 15 miles from any other hospital / CAH)
- **15 or fewer acute inpatient care beds** (or, up to 25 inpatient (swing) beds which can be used interchangeably for acute or SNF-level care, provided no more than 15 beds are used at any one time for acute care)
- **Restrict patient length of stay to no more than 96 hours** (per patient annual average) unless a longer period is required because of inclement weather or other emergency conditions, or a physician review organization (PRO) or other equivalent entity, on request, waives the 96-hour restriction
- Must offer 24-hour emergency services
- May be owned by a public, nonprofit, or for-profit entity

Source: http://www.aha.org/advocacy-issues/cah/history.shtml

Defining Rural- Scope of the Problem

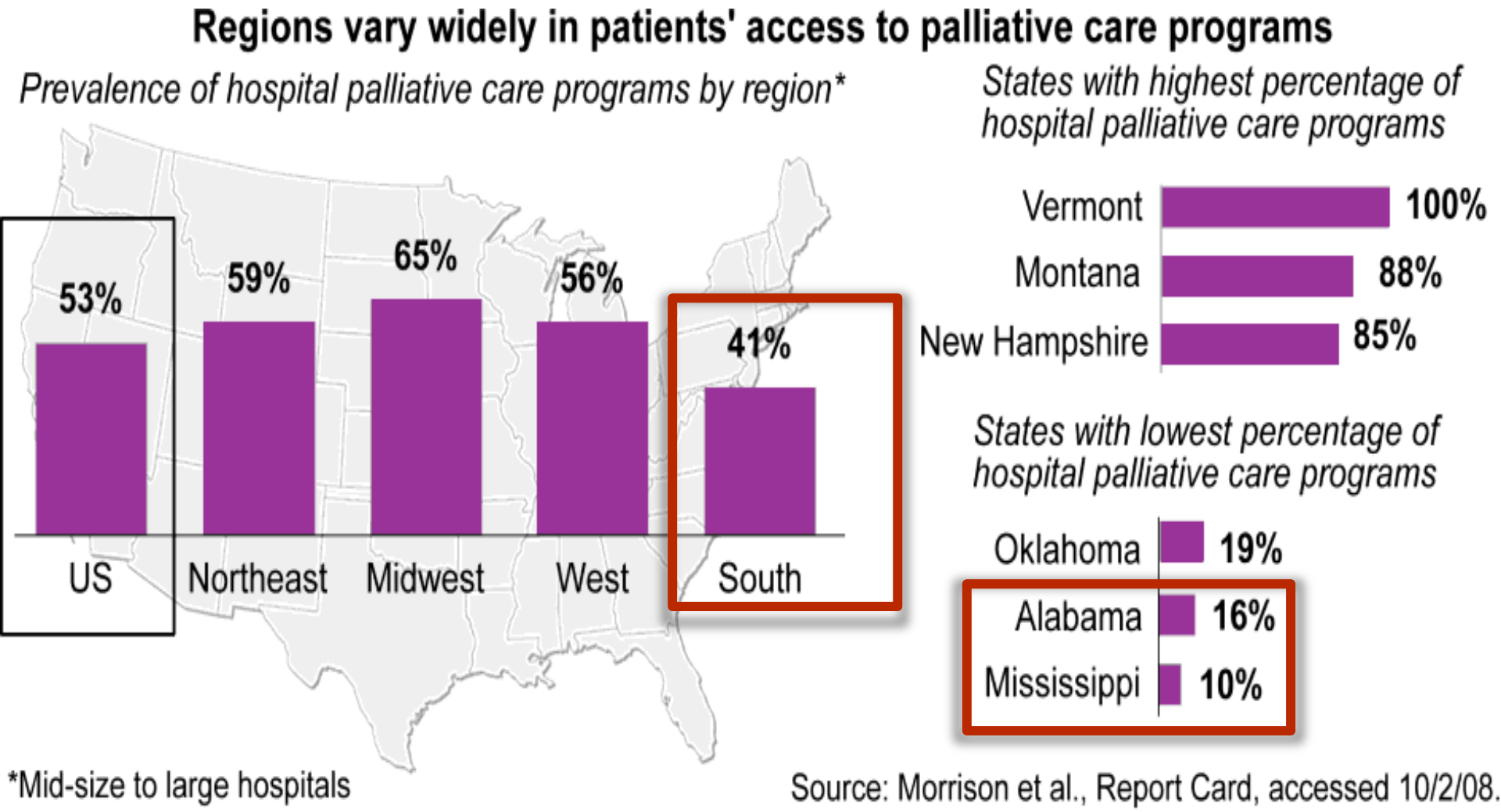


Rural Urban Commuting Area (RUCA) Classification

- Classify U.S. census tracts using measures of population density, urbanization, and daily commuting.
- Classified as:
  - Metropolitan (population 50,000 or greater)
  - Large Rural* (10,000 through 49,999)
  - Small Rural* town (2,500 through 9,999)
  - Isolated Small Rural* town (2499 or less)

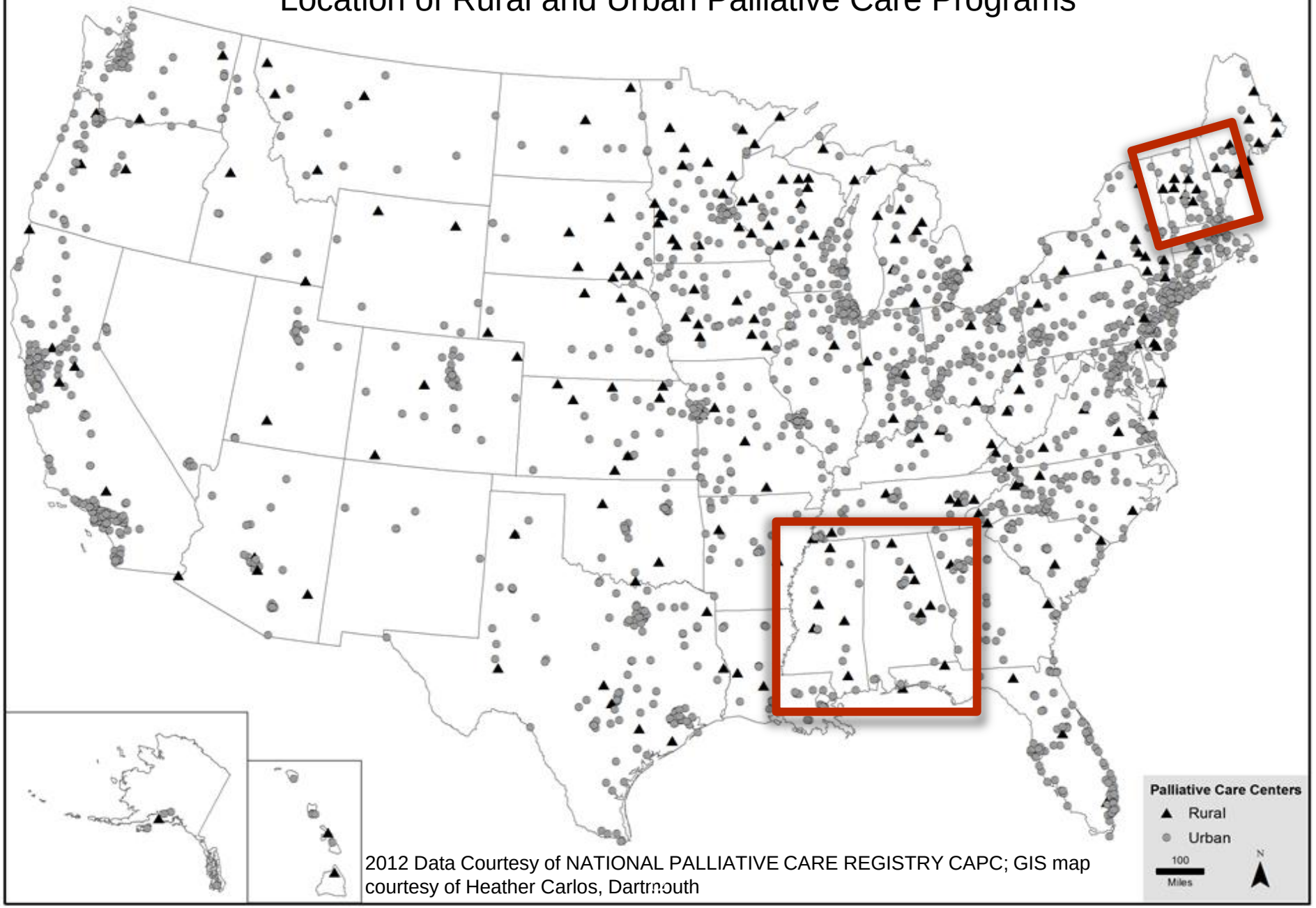
Rural is also referred to as “micropolitan” in some government schemas

Variability in Access to Palliative Care



Goldsmith B, Dietrich J, Qingling D, Morrison RS. Variability in access to hospital palliative care in the United States. Journal of Palliative Medicine 2008;11(8):1094-102.

Location of Rural and Urban Palliative Care Programs

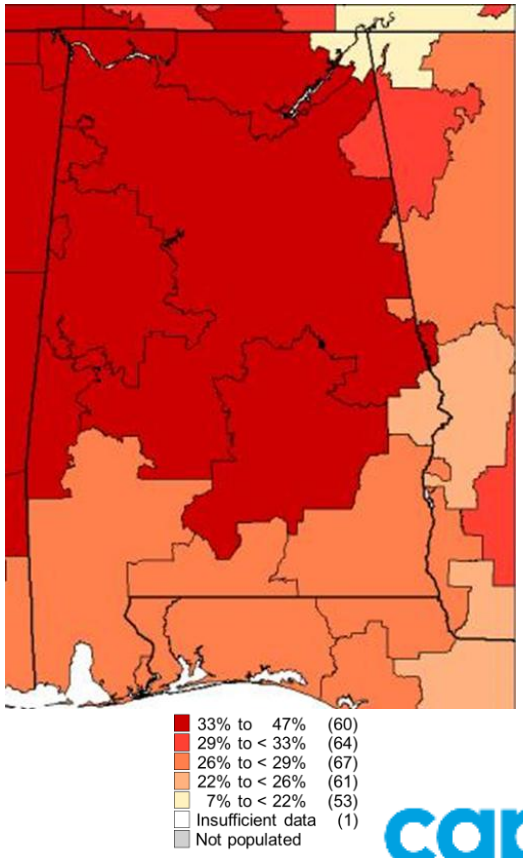


2012 Data Courtesy of NATIONAL PALLIATIVE CARE REGISTRY CAPC; GIS map courtesy of Heather Carlos, Dartmouth

There are relationships between rural locale, limited palliative care expertise, and suffering

55 of 67 Alabama counties are rural

Percent of cancer patients dying in hospital among hospital referral regions (2003-07)



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Barriers/Challenges to Rural Palliative

- **Patient Barriers**
  - Patient preference to stay in home community for care
  - Lack of transportation & long distances to palliative care centers (for patients or visitors)
  - Patient/clinician concerns that they will lose touch with community providers if they seek care at centers far from home

- **Provider Barriers**
  - Limited access to palliative care experts (only 22% of hospitals with <50 beds have PC)
  - Limited exposure to palliative patients in rural practices (1-2 deaths/year)
  - Limited availability of palliative care education for clinicians

- **Practice/System Barriers**
  - Poor communication/coordination of care between academic and rural community settings
  - Lack of availability of technology/techniques used for complex patient problems (e.g. pain pumps)
  - Few studies to identify 'best practices' or models for rural palliative care (e.g. no mention of rural in 3rd edition of National Consensus Guidelines; Limited mention in IOM "Dying in America" report
  - Few (reimbursement) incentives to keep patients in local community (e.g. critical access hospitals)

Data From: Fink et. al. JPM 2013; Ceronsky et al. 2013; CAPC Report Card 2011

Published Ahead of Print on February 6, 2012 as 10.1200/JCO.2011.38.5161
The latest version is at http://jco.ascopubs.org/cgi/doi/10.1200/JCO.2011.38.5161

JOURNAL OF CLINICAL ONCOLOGY

ASCO SPECIAL ARTICLE

American Society of Clinical Oncology Provisional Clinical Opinion: The Integration of Palliative Care into Standard Oncology Care

Thomas J. Smith, Sarah Temin, Erin R. Alesi, Amy P. Abernethy, Tracy A. Balboni, Ethan M. Basch, Betty R. Ferrell, Matt Loscalzo, Diane E. Meier, Judith A. Paice, Jeffrey M. Peppercorn, Mark Somerfield, Ellen Stovall, and Jamie H. Von Roenn

"…combined standard oncology care and palliative care should be considered early in the course of illness for ***any* patient with metastatic cancer and/or high symptom burden."**

*** No guidance on how to do this**

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Innovative Solutions / Exemplars

- Telehealth
- Community Lay Navigators

The ENABLE Telemedicine Intervention

- What is ENABLE and why/how evolved to telehealth approach?
- What are essential elements?
- How were nurse coaches trained?
- What were our outcomes
- Operational challenges
- Sustainability/Next steps-ACS Implementation Grant, heart failure; ASCO consensus opinion, RTIP

Project ENABLE

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

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

RWJ Cancer Center/ Hospice Collaboration Demonstration Projects (1999-2001)

- Norris Cotton Cancer Center
- University of Michigan Comprehensive Cancer Center
- Ireland Cancer Center, OH
- University of CA-Davis, CA

The Byrne Foundation

NORRIS COTTON CANCER CENTER

PROMOTING EXCELLENCE IN END-OF-LIFE CARE

A NATIONAL PROGRAM OF THE ROBERT WOOD JOHNSON FOUNDATION

RWJ Grantees

What is ENABLE?

- In-Person Psycho-educational Intervention
  - 4 structured sessions by palliative care APN
- "Charting Your Course"
  - Problem-solving/Behavioral Activation/
  - Empowerment
  - Symptom Management
  - Support and Communication
  - Advance Care Planning, loss, grief
- 'Regular' 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)

Bakitas M, Stevens M, Ahles T, et al. Project ENABLE: A palliative care demonstration project for advanced cancer patients in three settings. *J Palliat Med.* 2004;7(2):363-372

Charting Your Course

An Intervention for People Living with Cancer

PATIENT GUIDE

Version 4/14/2011

Communication, Support and Decision-Making

Chapter 3

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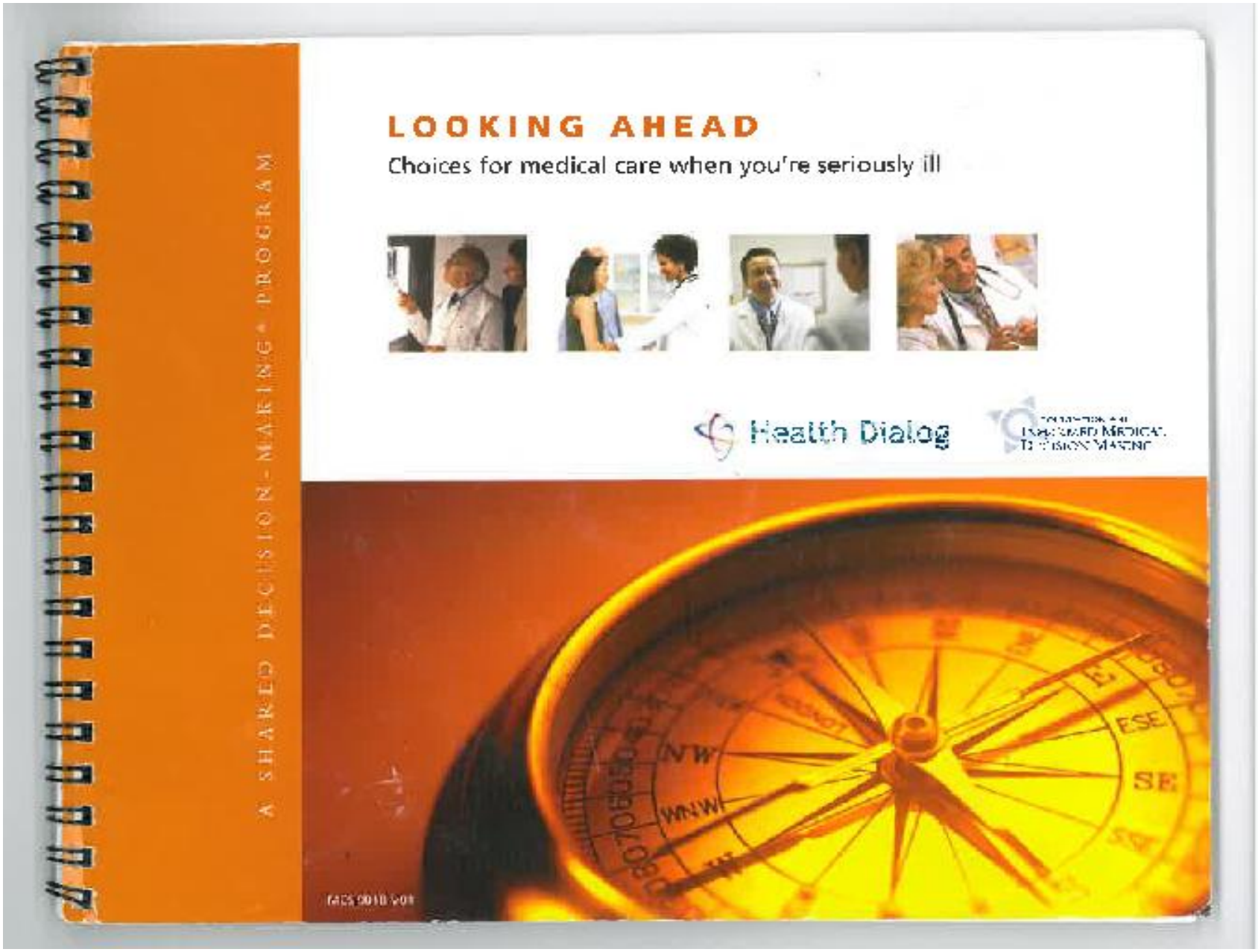
Shared Decision-Making Decision Aid (DVD & Booklet)



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

Are you leaning toward one option? ☒ No ☐ Yes, which one? _____

Certainty: Do you feel sure about the best choice for you? ☒ No ☐ Yes

Knowledge: Do you know which options are available to you? ☐ No ☒ Yes

Do you know <u>both</u> the benefits and risks of each option? ☒ No ☐ Yes

Values: Are you clear about which benefits and risks <u>matter most</u> to you? ☒ No ☐ Yes

A. In the balance scale below, list the options and main benefits and risks that you already know.
B. <u>Underline</u> 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.'

	Benefits (reasons to choose this option)	How much it matters (★)	Risks (reasons to avoid this option)	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 ★
	Breaking new ground	1 ★	At hospital longer	5 ★
Option 2 Best supportive care and standard chemotherapy	Benefit of treatment known	4 ★	??? of benefit not great	4 ★
	Side effects known	4 ★	Side effects	2 ★
	Less time at hospital	4 ★	Still at hospital	2 ★
Option 3 Best supportive care only	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 ★

Why a Telehealth/Telephone Intervention?

Project ENABLE: A Palliative Care Demonstration Project for Advanced Cancer Patients in Three Settings

MARIE BAKITAS, M.S., A.R.N.P.,[1] MARGUERITE STEVENS, Ph.D.,[1] TIM AHLES, Ph.D.,[1] MARIE KIRN, M.A.,[2] KAREN SKALLA, M.S., A.R.N.P.,[1] NANCY KANE, M.S., R.N.,[3] and E. ROBERT GREENBERG, M.D.[1] for the Project ENABLE Co-investigators[3*]

JOURNAL OF PALLIATIVE MEDICINE
Volume 7, Number 2, 2004

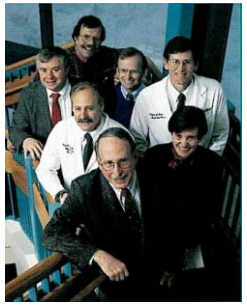
Proxy Perspectives Regarding End-of-life Care for Persons With Cancer

CANCER, (2008) VOL.112; 1854–61

Marie Bakitas, DNSc, ARNP[1,2,3]
Tim A. Ahles, PhD[4]
Karen Skalla, MSN, ARNP[5]
Frances C. Brokaw, MD, MS[2,6]
Ira Byock, MD[2,3]
Brett Hanscom, MS[7]
Kathleen Doyle Lyons, ScD, OTR[8]
Mark T. Hegel, PhD[8]

ENABLE I CONCLUSIONS

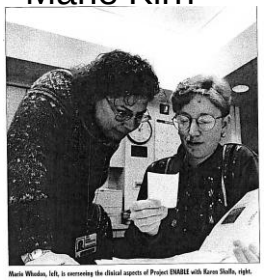
- Established feasibility of early intervention, concurrent palliative / oncology care model
- Compared to Local and National Benchmarks
  - Increased rate of ADs and improved clinician/pt communication about EOL care
  - Increased rate of home death
  - Decreased rates of hospital and nsg home deaths
  - Increased Hospice involvement and average LOS



Cancer Center Director
Greenberg, Stevens

Hospice Director, Marie Kirn

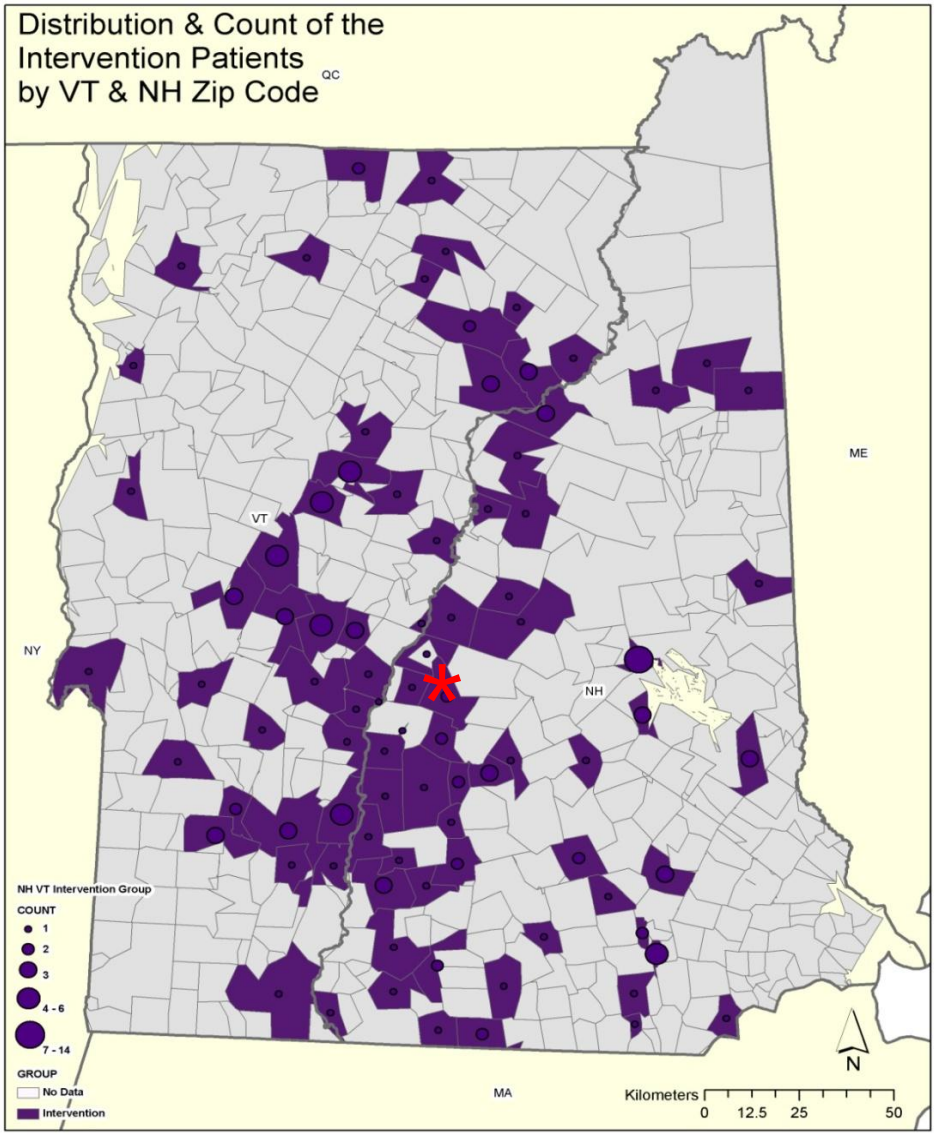
Psycho-onc Rsch
Tim Ahles, PhD

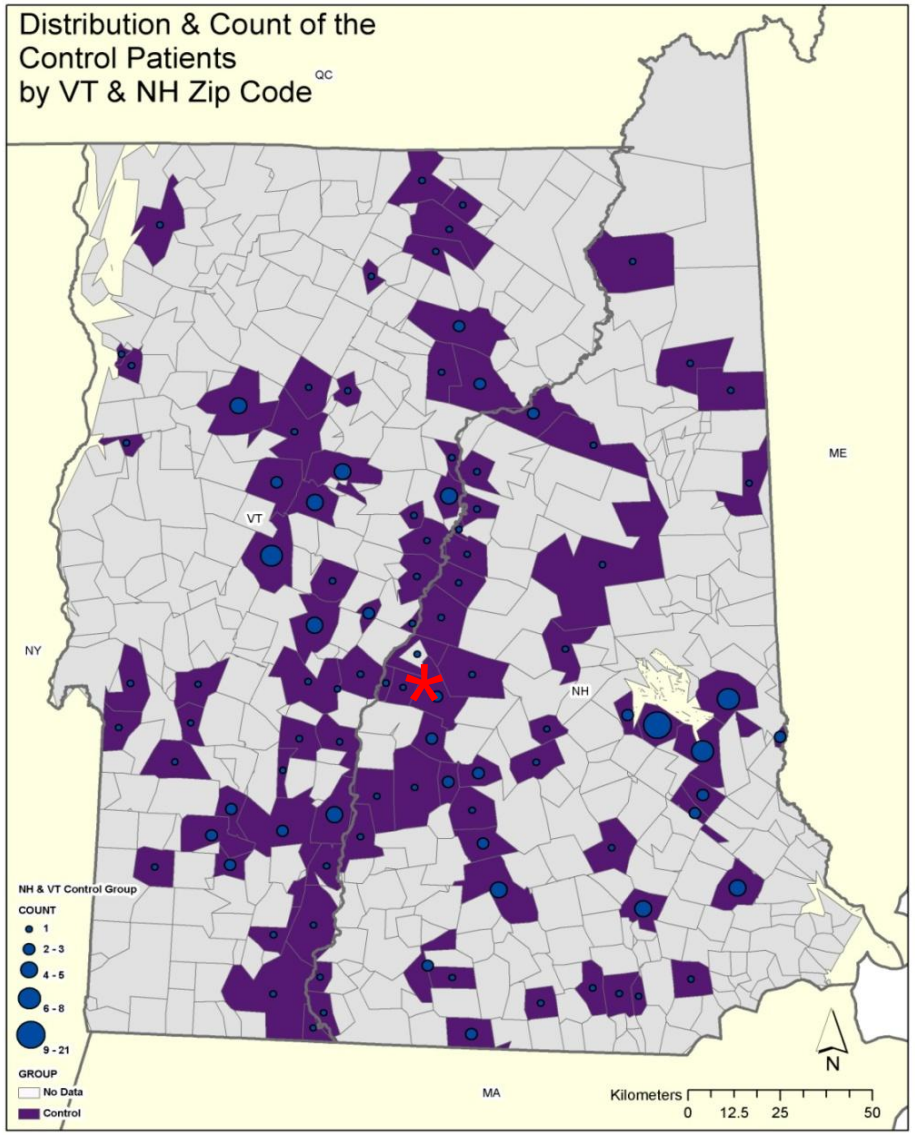


Proj. Coordinator
Bakitas, Skalla

***BUT ONLY HALF OF PARTICIPANTS COULD GET TO IN-PERSON SESSIONS**

Why a Telehealth/Telephone Intervention?





60% of patients served were “rural”

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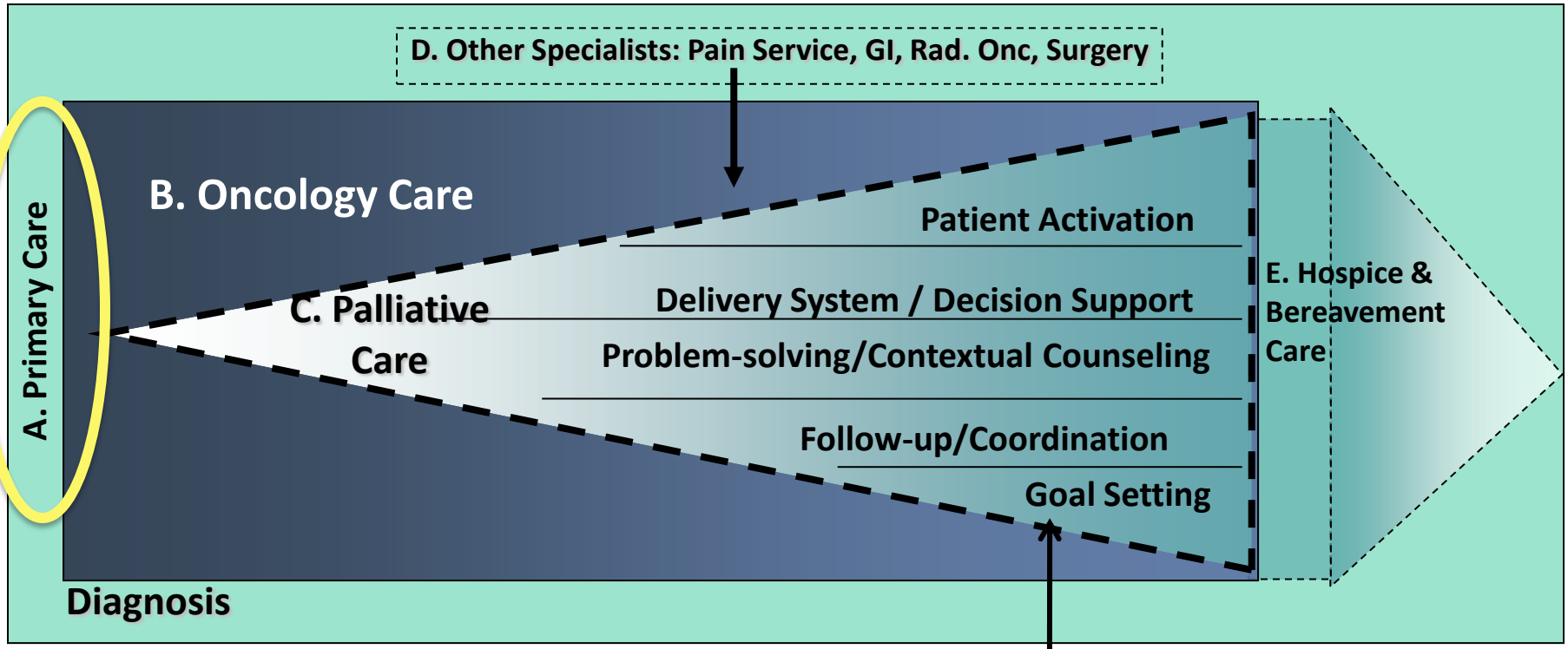
2009 Courtesy of Jennifer Alford-Teaster, GIS/Spatial Analysis Specialist, Department of Geography, Dartmouth College

ENABLE Essential Elements

1. **Trigger mechanism** to identify patients near diagnosis
2. Offer ENABLE to patient **& primary family caregiver**
3. Perform standardized **in-person palliative care assessment**
4. Provide **coaching** (in person or phone) on core topics:
   - -The COPE attitude and problem-solving support
   - -Symptom management, self-care, **identify local resources**
   - -Communication, Decision-Making, Advance Care Planning
   - -Life review, Forgiveness, Creating a Legacy
5. Provide **regular follow-up** & family bereavement support

ENABLE Essential Elements: Conceptual Foundation



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How were NURSE COACHES Trained?

- APNs with palliative care specialty training
- 20-24 hours self-study, didactic, role play
  - Problem solving/COPE
  - Shared decision-making
  - Outlook
- Recorded mock sessions with another team member followed by feedback & supervision
- Reversed roles
- On-going weekly team meeting & supervision

Results

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

Results

- This early palliative care telehealth intervention improved **QOL (*P*=0.02)** and **mood (*P*=0.02).**
- Further study is needed to consistently improve symptom intensity (*P*=0.06).
- Concerns about palliative care "shortening survival" are unfounded & opposite may be true

JAMA

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2009;302:741-749

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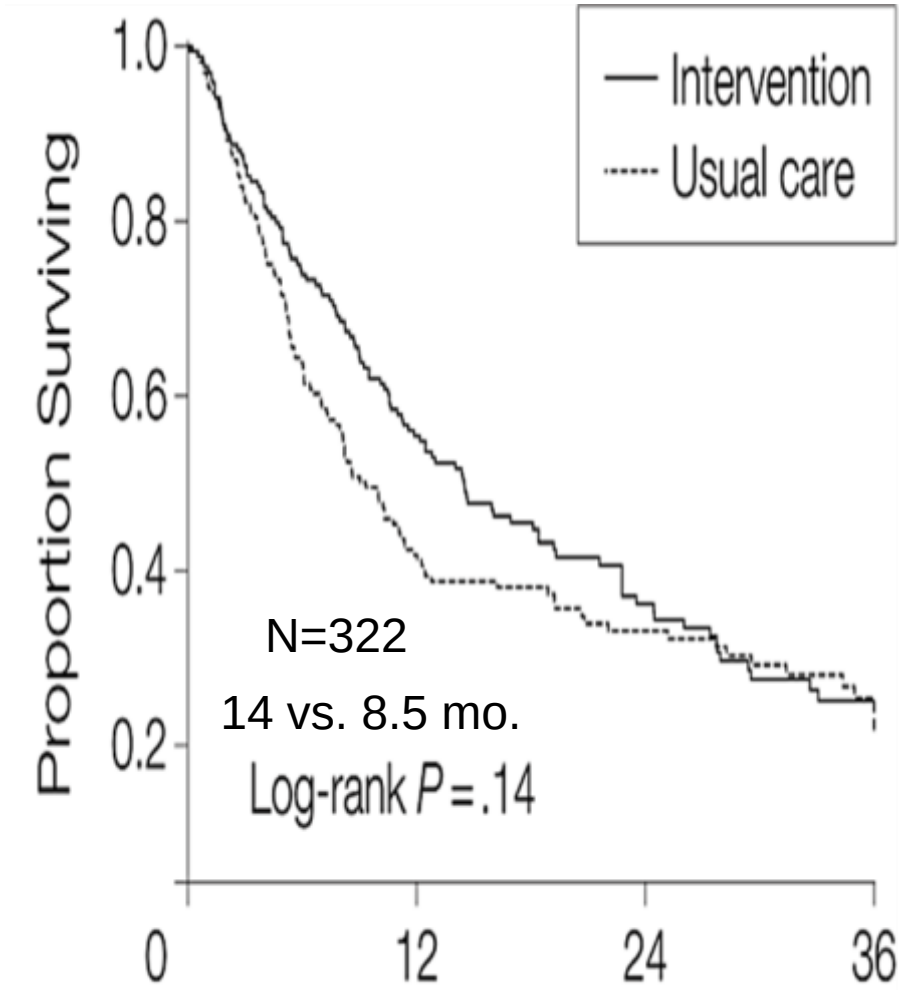
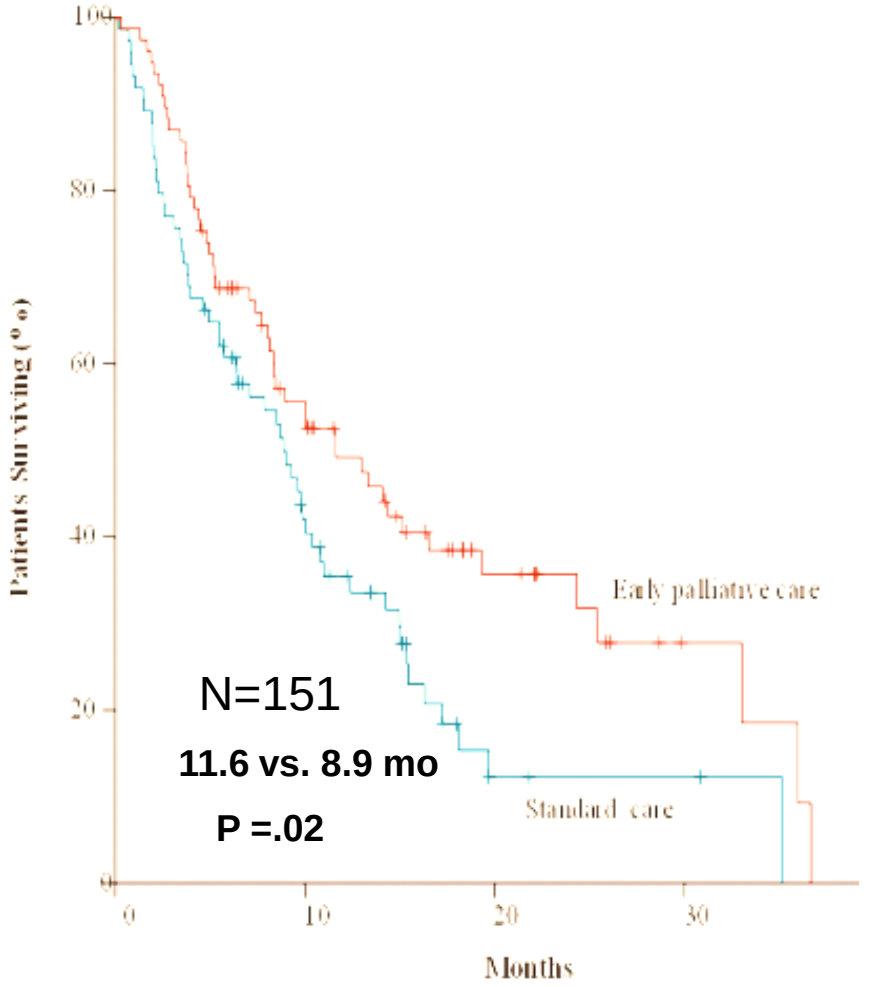
What were our Results?

Kaplan–Meier Estimates of Survival According to Study Group





Bakitas M, Lyons K, Hegel M, et al. *JAMA.* 2009;302(7):741-749.

Temel JS, Greer JA, Muzikansky A, et al. *N Engl J Med.* Aug 19 2010;363(8):733-742.

What were our Results?

Published Ahead of Print on March 23, 2015 as 10.1200/JCO.2014.58.6362
The latest version is at http://jco.ascopubs.org/cgi/doi/10.1200/JCO.2014.58.6362

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, J. Nicholas Dionne-Odom, and Andres Azuero, University of Alabama at Birmingham, Birmingham, AL; Marie A. Bakitas, Jennifer Frost, and Konstantin H. Dragnev, Dartmouth-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,

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
JCO.2014.58.7

Published Ahead of Print on March 23, 2015 as 10.1200/JCO.2014.58.7824
The latest version is at http://jco.ascopubs.org/cgi/doi/10.1200/JCO.2014.58.7824

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

and article

Published Ahead of Print on March 23, 2015 as 10.1200/JCO.2014.60.5386
The latest version is at http://jco.ascopubs.org/cgi/doi/10.1200/JCO.2014.60.5386

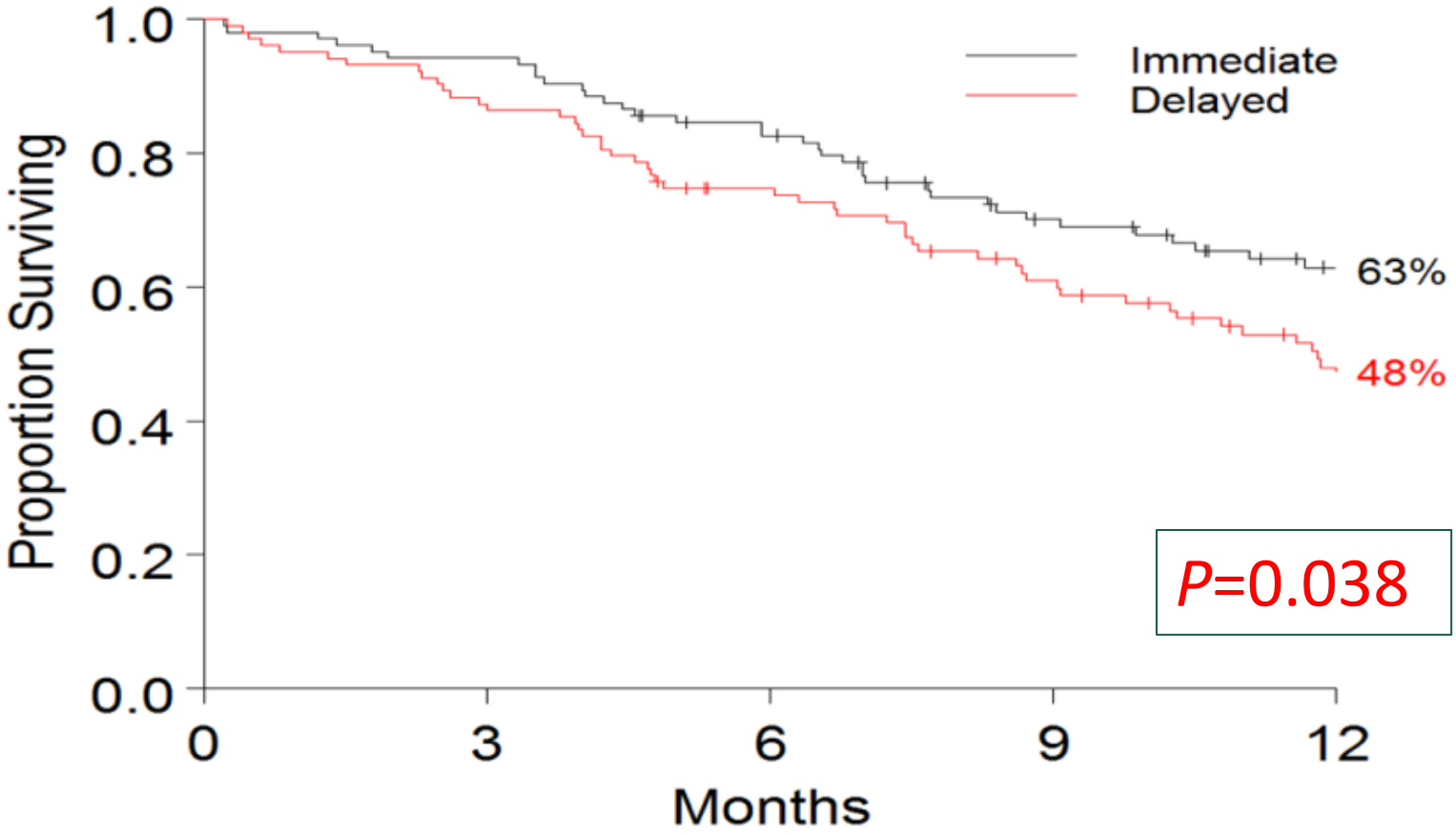
JOURNAL OF CLINICAL ONCOLOGY | EDITORIAL

Palliative Care: If It Makes a Difference, Why Wait?

Barbara Gomes, *King's College London, Cicely Saunders Institute, London, United Kingdom*

See accompanying articles doi: 10.1200/JCO.2014.58.6362 and doi: 10.1200/JCO.2014.58.7824

What were our Results?



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

Bakitas et al. (2015, in press) Journal of Clinical Oncology

What are Operational Challenges of Telehealth in Rural Areas?

- Patient “No shows”
- Hearing issues / not a “phone” person
- Literacy
- Low attendance at phone “groups”
- Limited cell service, cell phone per minute charges
- Limited internet connections

Sustainability/Next Steps

- RTIP Program
- Implementation study (cancer) in 4 sites via a Virtual Learning Collaborative
  - American Cancer Society RSG-"Reducing disparities in patients and caregivers with advanced cancer"
  - Evaluating different models including consideration of lay navigators and interdisciplinary teams
- Translation from cancer to heart failure
  - National Palliative Care Research Center
    - 25 dyads in 2 sites
  - ENABLE CHF PC-R0-1 (NINR funded Jan. 2015-2020)

NATIONAL CANCER INSTITUTE

Research-tested Intervention Programs (RTIPs)
RTIPs - Moving Science into Programs for People

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Project ENABLE II

On This Page

Highlights

Program Title	Project ENABLE II
Purpose	Designed to enhance the quality of life for cancer survivors. *(2009)*
Program Focus	Psychosocial - Coping
Population Focus	Cancer Survivors
Topic	Survivorship
Age	Adults (40-65 years), Older Adults (65+ years), Young Adults (19-39 years)
Gender	Female, Male
Race/Ethnicity	Alaskan Native, American Indian, Asian, Black, not of Hispanic or Latino origin, Hispanic or Latino, Pacific Islander, White, not of Hispanic or Latino origin
Setting	Clinical, Community, Home-based, Rural, Suburban, Urban/Inner City
Origination	United States
Funded by	NCI (Grant number(s): R01CA101704)

Products

Preview, download, or order free materials on CD-ROM

Browse more programs on **Survivorship**

Learn more about this program and the P.I. on R2R's Featured Partner page

RTIPs Scores

This program has been rated by external peer reviewers. Learn more about RTIPs program review ratings.

- **Research Integrity** 4.8
- **Intervention Impact** 3.0
- **Dissemination Capability** 4.5

(1.0 = low 5.0 = high)

RE-AIM Scores

This program has been evaluated on criteria from the RE-AIM framework, which helps translate research into action.

- **Reach** 100.0%
- **Effectiveness** 100.0%
- **Adoption** 16.7%
- **Implementation** 71.4%

+ Expand All Sections Below

The Need

The American Cancer Society estimates that 11.1 million Americans were living with cancer in 2005, and that 1.5 million new cases of cancer were diagnosed in 2009. Fifty percent of persons with cancer are not cured of their disease, and each year more than a half million people die of cancer in the United States. However, with improved treatment, even patients with advanced disease may live for years. Providing palliative care at the same time as oncology treatment (e.g., chemotherapy, radiation)

... Show more

Back to Top

The Program

Description

Project ENABLE ("Educate, Nurture, Advise Before Life Ends") uses a case management, educational approach to encourage patient activation, self-management, and empowerment among individuals with a new diagnosis of advanced stage or recurrent cancer. The manualized, telephone-based intervention is designed to improve problem-solving skills, symptom management, and communication skills, as well as to promote advance care planning (e.g., advanced directives and "do not resuscitate" orders). The intervention ... Show more

Implementation Guide

The Implementation Guide is a resource for implementing this program. It provides important information about the staffing and functions necessary for administering this program in the user's additionally, the steps needed to carry out the research-tested program, relevant program

RE-AIM Notes Hide / View Notes

Use this area to take notes about how this program might work for you. Read More about RE-AIM.

Reach

Absolute number, proportion and representativeness of individuals who participate in the program

Total # of people who could benefit: (Max. 5 characters)

Total # of people you could reach: (Max. 5 characters)

Your demographic focus: (No max # of characters)

Barriers to reaching your target population: (No max # of characters)

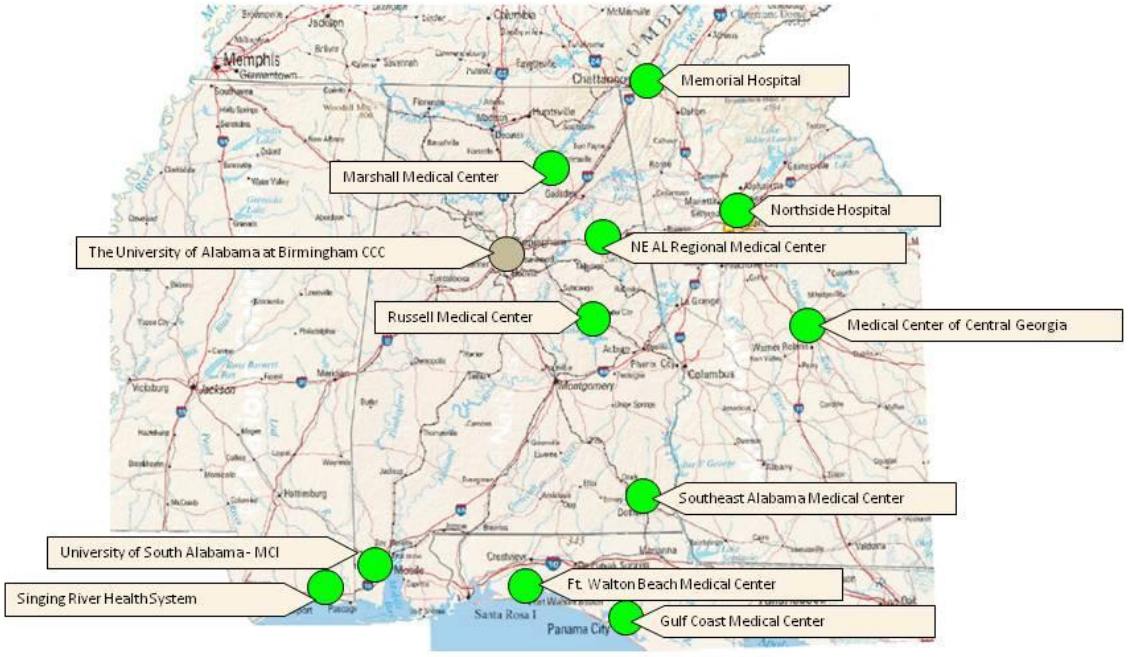
Effectiveness

Palliative Care in the Deep South

Patient Care Connect: Lay Navigators supporting cancer patients across the illness continuum

This project described was supported by Grant Number 1C1CMS331023 from the Department of Health and Human Services, centers for Medicare & Medicaid Services. The contents of this presentation are solely the responsibility of the authors and do not necessarily represent the official views of the U.S. department of Health and Human Services of any of its agencies.

UAB Health System Cancer Community Network

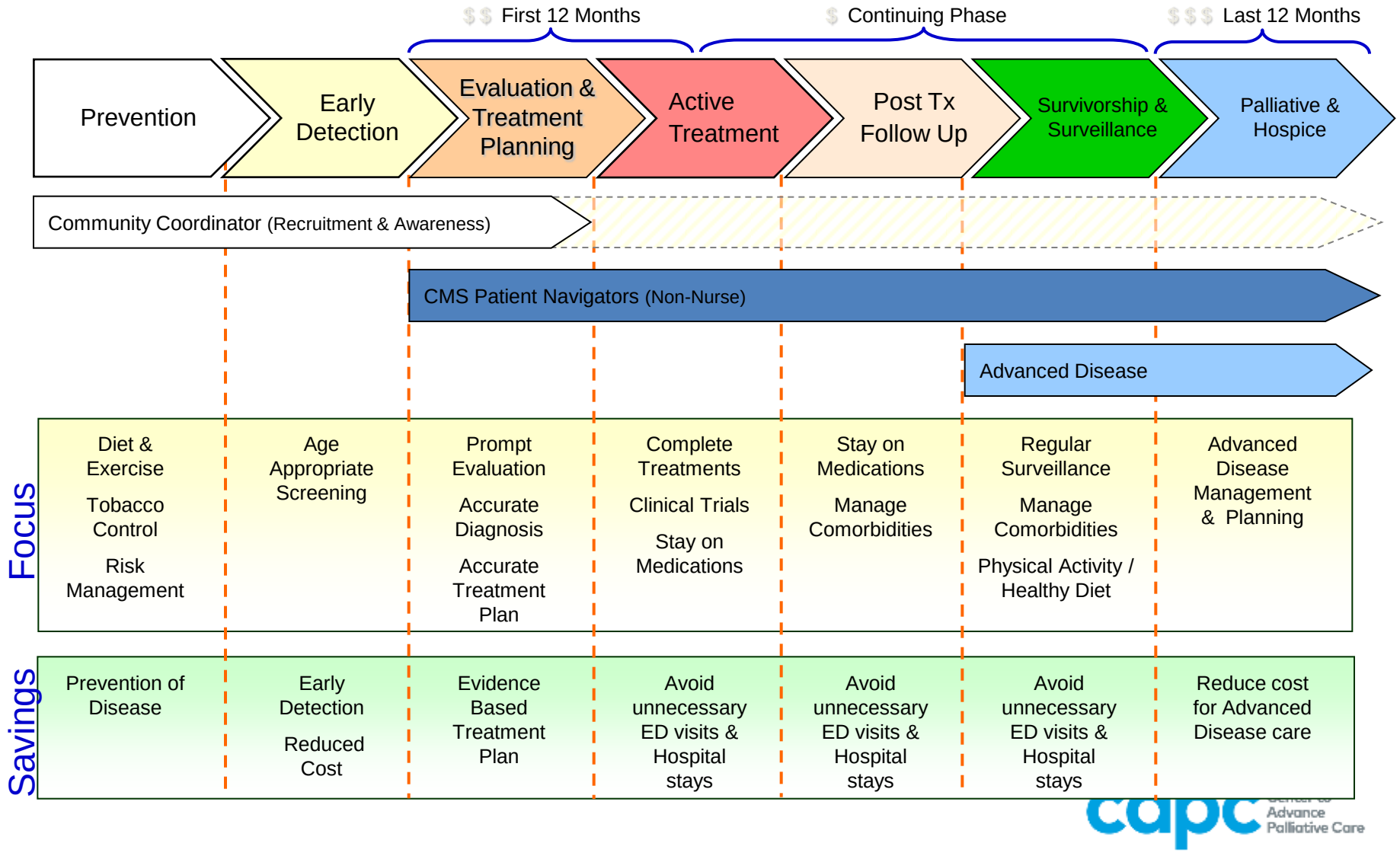


capc Center to Advance Palliative Care

Program Goals

- Reduction in Emergency Room visits.
  - Reduction in unnecessary hospital days.
  - Reduction in unnecessary ICU days.
- Encourage evidence based clinical pathways.
- Encourage earlier adoption of hospice care.
  - Reduce use of chemotherapy in last 2 weeks of life.
- Provide the highest quality of life for people diagnosed with cancer.

Full Continuum of Care



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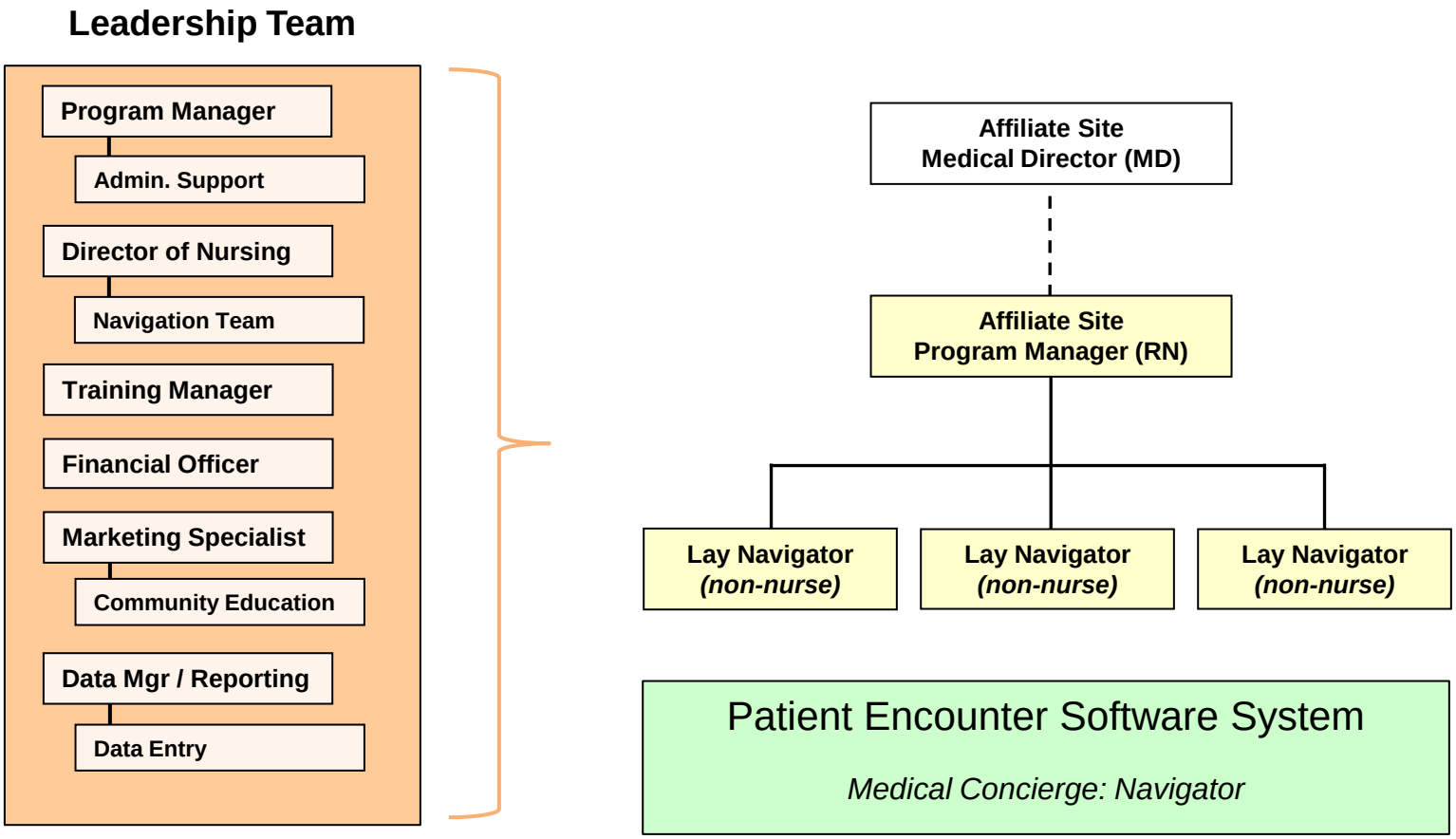
Eligibility Criteria

- Medicare Patient
  - Primary A and/or B
- Age ≥ 65
- Cancer Diagnosis
  - Pathology required

Navigation Teams



Lay Navigators to Extend the Reach of Palliative Care

- Non-healthcare professions
- Established members of the community they serve
- Specifically recruit community members who are “natural helpers”
- Sites were responsible for recruiting: “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…)

Navigator Training

- 5 days face to face training and team building sessions
- Ongoing training in person and webinars
- Content included training on:
  - Conceptual Model for program/Multilevel Interventional Model
  - Core Concepts of: Health, Health Promotion and Empowerment
  - Navigation History
  - Navigator role and responsibilities
  - Boundaries
  - Geriatric basics
  - Cancer basics
  - Advanced cancer
  - Multi-morbidities
  - Symptom burden (pain, fatigue, etc.)
  - Communication Skills
  - Health Literacy
  - Advance care planning
  - Documentation/tool usage

PCC Curriculum

PROJECT

Project 101

CMS Program Overview
Goals and AIMs
Definition of HEALTH/EMPOWERMENT
Definition of DISTRESS
Definition of HEALTH PROMOTION
Definition of HEALTH LITERACY

PATIENT

PATIENT 101

Intro to Medicare Insurance

GERIATRICS 101

Overview to Geriatrics
Geriatric Communications
Geriatric Sensory

CANCER 101

What is Cancer?
Advanced Illness
Multidimensional Aspects of Cancer

PATIENT 201

Expanded Medicare Insurance

GERIATRICS 201

Comorbid Conditions
3 D's
Nutrition in the Geriatric Patient
Preventing Decline in Patient's ADLs
Geriatric Ethical Issues
Geriatric Exercise Module
Pain Management
Fatigue Management

CANCER 201

Hem. Malignancies
Head & Neck
Lung
Chemo brain
ACS Resources

NAVIGATION

NAVIGATION 101

CMS Program Roles & Responsibilities
Case Mgt Approach to Navigation
Problem Solving Process
Effective Communications
Difficult Conversations-Advanced Illness
Finding Resources

NAVIGATION 201

Compassionate Conversations
Compassion Fatigue & Boundaries
Direct Care - Care Transition
Advanced Care Planning & Skill Building

Respecting Choices

Online training modules (6)
In person training
Role play exercises

TOOLS/PROCESSES

TOOLS 101

Distress Thermometer
Care Maps
Medical Concierge
MOOP

TOOLS 201

KATZ score

Navigator Role

- EMPOWERS patients to:
  - Identify and connect to resources
  - Communicate desires and goals
  - Recognize clinical symptoms
  - Understand disease and treatment
  - Engage in end-of-life discussions with their providers
  - Take an active role in their healthcare

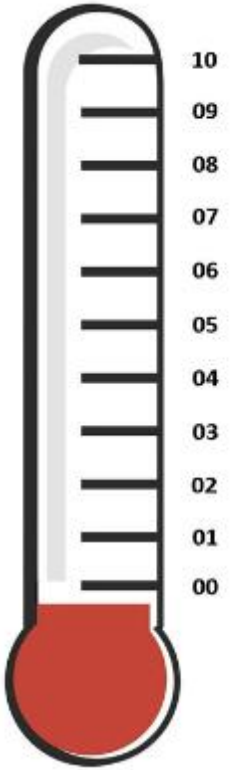
Navigator Role

- 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

Distress Survey

- Identifies the level of distress
- Guides interview/conversation
- Allows PROACTIVE detection and intervention
- Drives resource identification for patient reported barriers
  - Professional referral
  - Interventions
- Drives data collection

Distress Survey



PRACTICAL PROBLEMS:

___Ability to use Phone ___Child Care ___Cooking
___Getting Groceries/Shopping ___Housekeeping ___Housing
___Insurance/Financial ___Manage Finances ___Transportation
___Work

FAMILY PROBLEMS:

Dealing with: ___Children ___Family Support
___Friends ___Partner

INFORMATION CONCERNS:

Lack of Info About (my):
___Alternative Therapy Choices ___Diagnosis/Disease ___Diagnostic Results
___Diet/Nutrition ___End of Life Issues ___Hospice
___Home Health ___Legal Issues
___Maintaining Fitness/Exercise ___Performing Medical Procedures
___Prognosis ___Scheduling ___Survivorship
___Side-Effects/Treatment(s) ___Side-Effects/Medication(s)
___Supportive Care ___Treatment(s) ___Treatment Decisions

COGNITIVE PROBLEMS:

___Feeling Confused ___Forgetfulness ___Poor Thinking
___Memory/Concentration ___Seeing Things/Hearing Things
___Understanding Verbal or Written Words

OTHER:

___Ability to Read/Write ___Cultural/Religious Needs
___Citizenship ___Lack of Social Support
___Language Barrier ___Post-op Care

PHYSICAL PROBLEMS:

___Balance/Walking & Mobility Difficulty ___Bathing/Dressing
___Body Sores ___Breathing
___Changes in Urination ___Constipation
___Controlling Bowel Movement ___Controlling Urination
___Diarrhea ___Dizziness ___Eating
___Fatigue ___Feeding Self ___Fever
___Getting Around- Inside Home ___Getting Around- Outside Home
___Hearing ___Indigestion ___Mouth Sores
___Loss of Appetite ___Moving In/Out of Chair or Bed
___Nausea/Vomiting ___Nose Dry/Congested
___Opening Medication Bottles ___Pain ___Sexual Problems
___Skin Dry/Itchy ___Sleep/Insomnia ___Substance Abuse
___Swallowing ___Swollen Arms/Legs ___Talking
___Tingling Hands/Feet ___Toileting ___Vision
___Weight Change ___Writing

EMOTIONAL PROBLEMS:

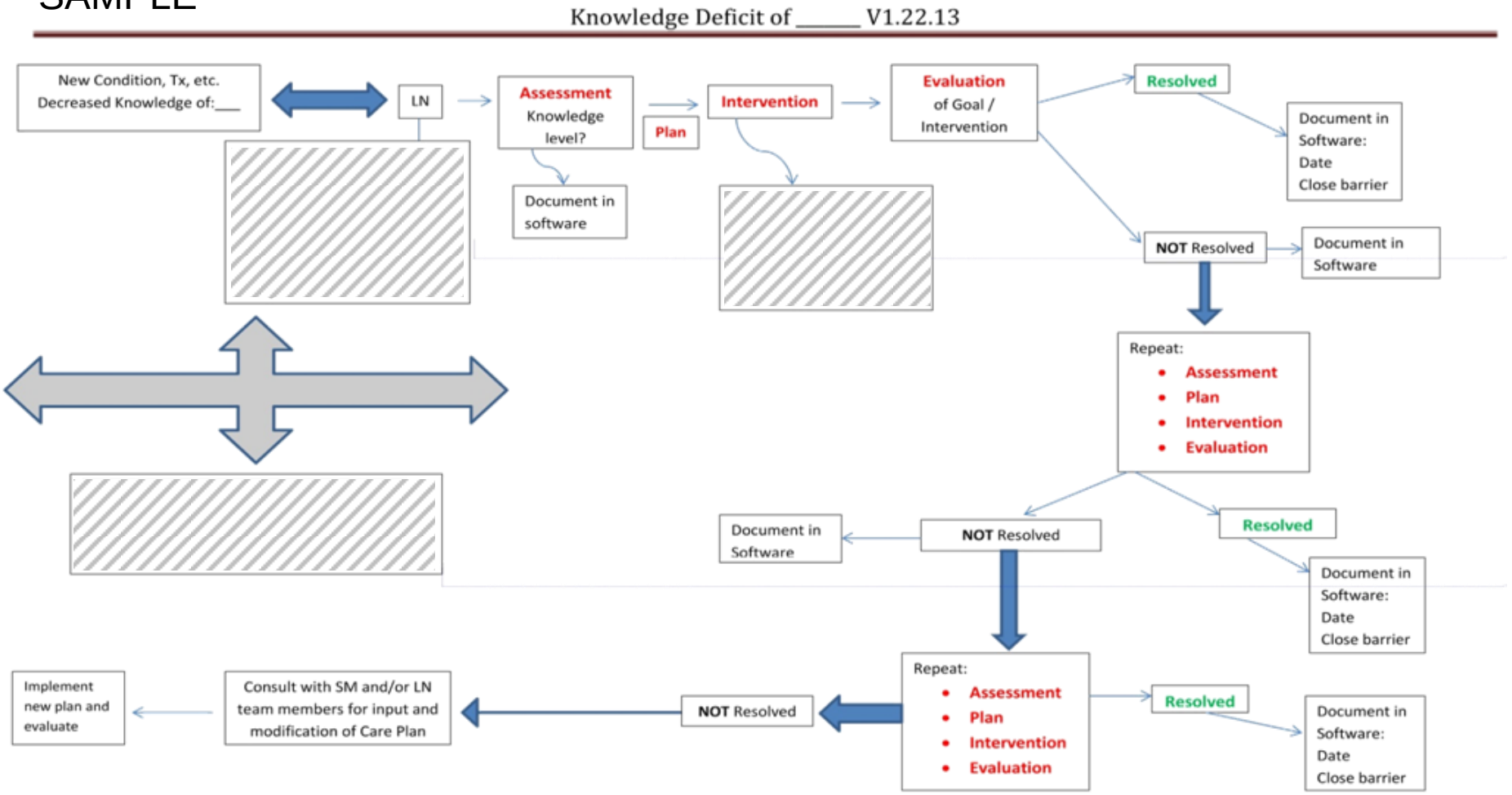
___Adjusting to Changes in Appearance ___Adjusting to my Illness
___Boredom ___Concentration
___Coping with Grief & Loss ___Emotional Control ___Fear(s)
___Feeling Depressed or "Blue" ___Feeling Hopeless ___Guilt
___Intrusions (thoughts that appear suddenly and repeatedly that are not welcome)
___Isolation/Feeling Alone ___Loss of Interest in Usual Activities
___Managing Stress ___Nervous/Anxiety
___Role Changes ("Caring for Family") ___Sadness
___Self-esteem ___Worry

SPIRITUAL/RELIGIOUS CONCERNS:

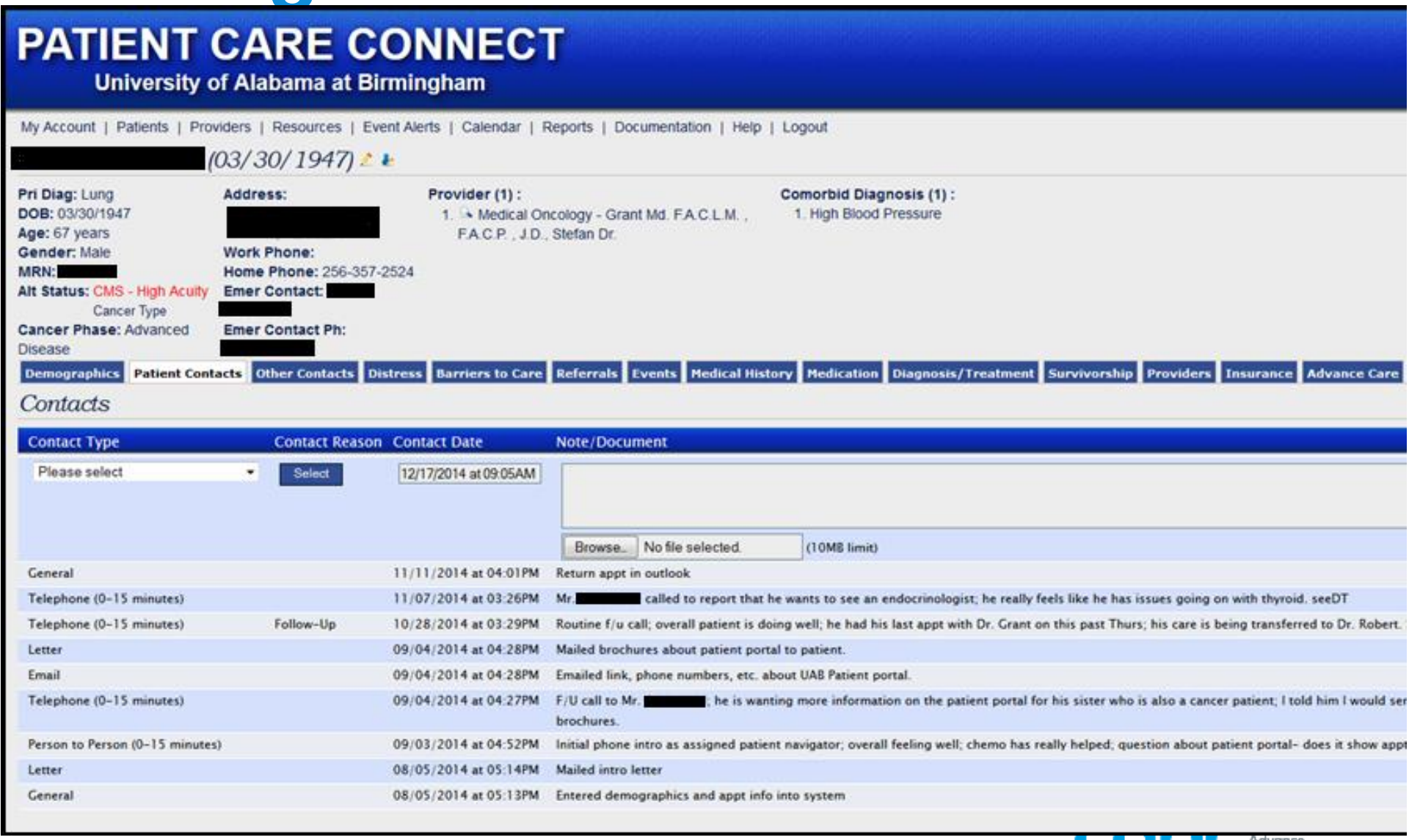
___Lack of Comfort, Strength or Hope from Spiritual Beliefs
___Facing my Mortality ___Lack of Support from Spiritual/Religious Group
___Loss of Faith ___Trust in God ___Loss of Sense of Purpose
___Meaning of Life ___Relating to God

Care Maps

SAMPLE



Navigation Software



PATIENT CARE CONNECT
University of Alabama at Birmingham

My Account | Patients | Providers | Resources | Event Alerts | Calendar | Reports | Documentation | Help | Logout

[redacted] (03/30/1947)

Pri Diag: Lung
DOB: 03/30/1947
Age: 67 years
Gender: Male
MRN: [redacted]
Alt Status: CMS - High Acuity
Cancer Type [redacted]
Cancer Phase: Advanced Disease

Address: [redacted]
Work Phone:
Home Phone: 256-357-2524
Emer Contact: [redacted]
Emer Contact Ph: [redacted]

Provider (1) :
1. Medical Oncology - Grant Md. F.A.C.L.M. , F.A.C.P. , J.D., Stefan Dr.

Comorbid Diagnosis (1) :
1. High Blood Pressure

Demographics | Patient Contacts | Other Contacts | Distress | Barriers to Care | Referrals | Events | Medical History | Medication | Diagnosis/Treatment | Survivorship | Providers | Insurance | Advance Care

Contacts

Contact Type	Contact Reason	Contact Date	Note/Document
Please select	Select	12/17/2014 at 09:05AM	Browse.. No file selected. (10MB limit)
General		11/11/2014 at 04:01PM	Return appt in outlook
Telephone (0-15 minutes)		11/07/2014 at 03:26PM	Mr. [redacted] called to report that he wants to see an endocrinologist; he really feels like he has issues going on with thyroid. seeDT
Telephone (0-15 minutes)	Follow-Up	10/28/2014 at 03:29PM	Routine f/u call; overall patient is doing well; he had his last appt with Dr. Grant on this past Thurs; his care is being transferred to Dr. Robert.
Letter		09/04/2014 at 04:28PM	Mailed brochures about patient portal to patient.
Email		09/04/2014 at 04:28PM	Emailed link, phone numbers, etc. about UAB Patient portal.
Telephone (0-15 minutes)		09/04/2014 at 04:27PM	F/U call to Mr. [redacted]; he is wanting more information on the patient portal for his sister who is also a cancer patient; I told him I would ser brochures.
Person to Person (0-15 minutes)		09/03/2014 at 04:52PM	Initial phone intro as assigned patient navigator; overall feeling well; chemo has really helped; question about patient portal- does it show appt
Letter		08/05/2014 at 05:14PM	Mailed intro letter
General		08/05/2014 at 05:13PM	Entered demographics and appt info into system

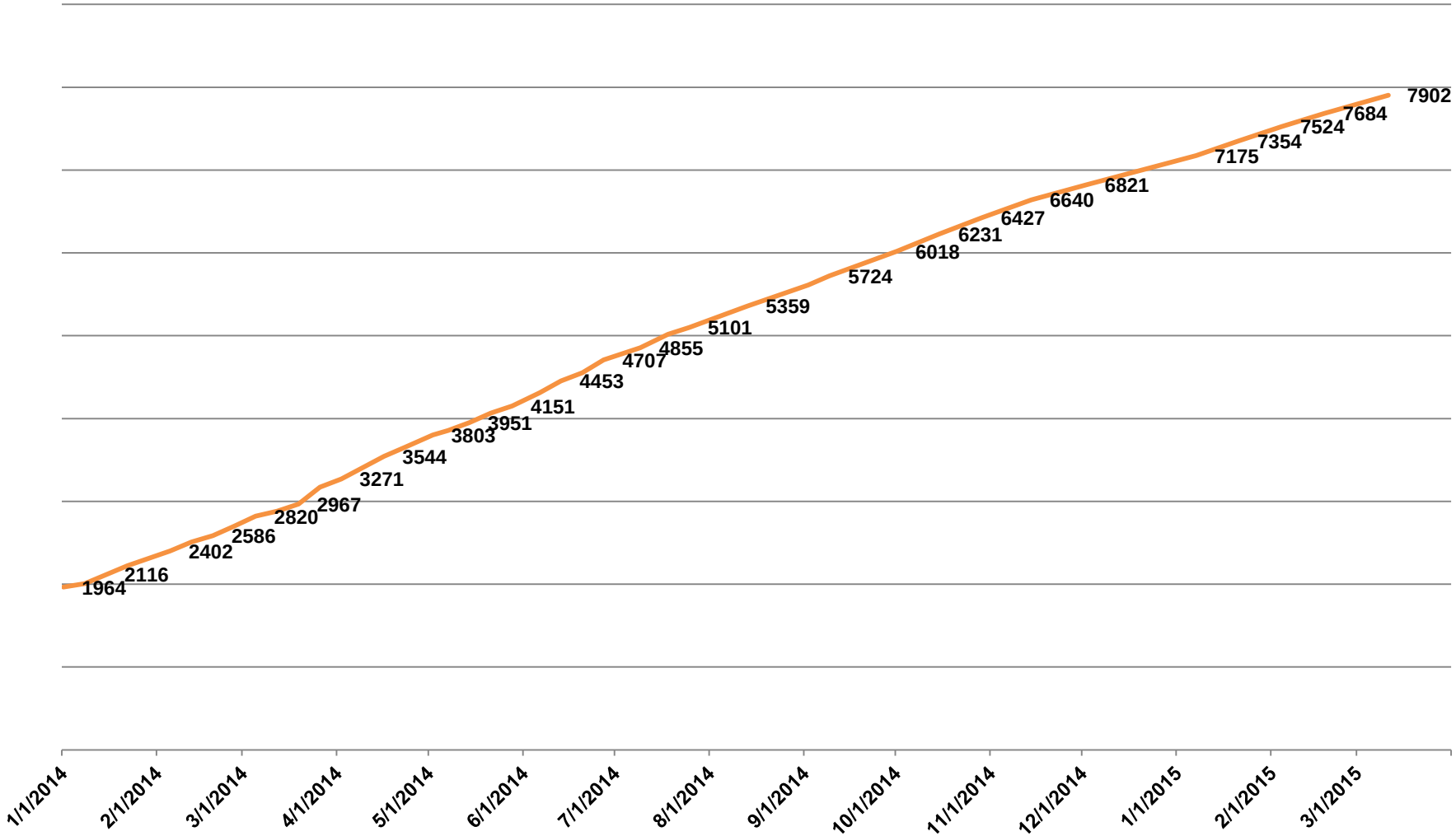
Navigator Activities

- Keeping patients out of the ER:
  - Proactive identification of symptom issues
  - Point of contact to guide resource utilization
    - Anxious patient having a panic attack

- Providing Continuity:
  - Inpatients with changing teams
  - Hospice patients- providing feedback to primary MD

- Assisting with Access:
  - Transition from surgical team to Medical Oncology

PCC Enrollment



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Patient Characteristics

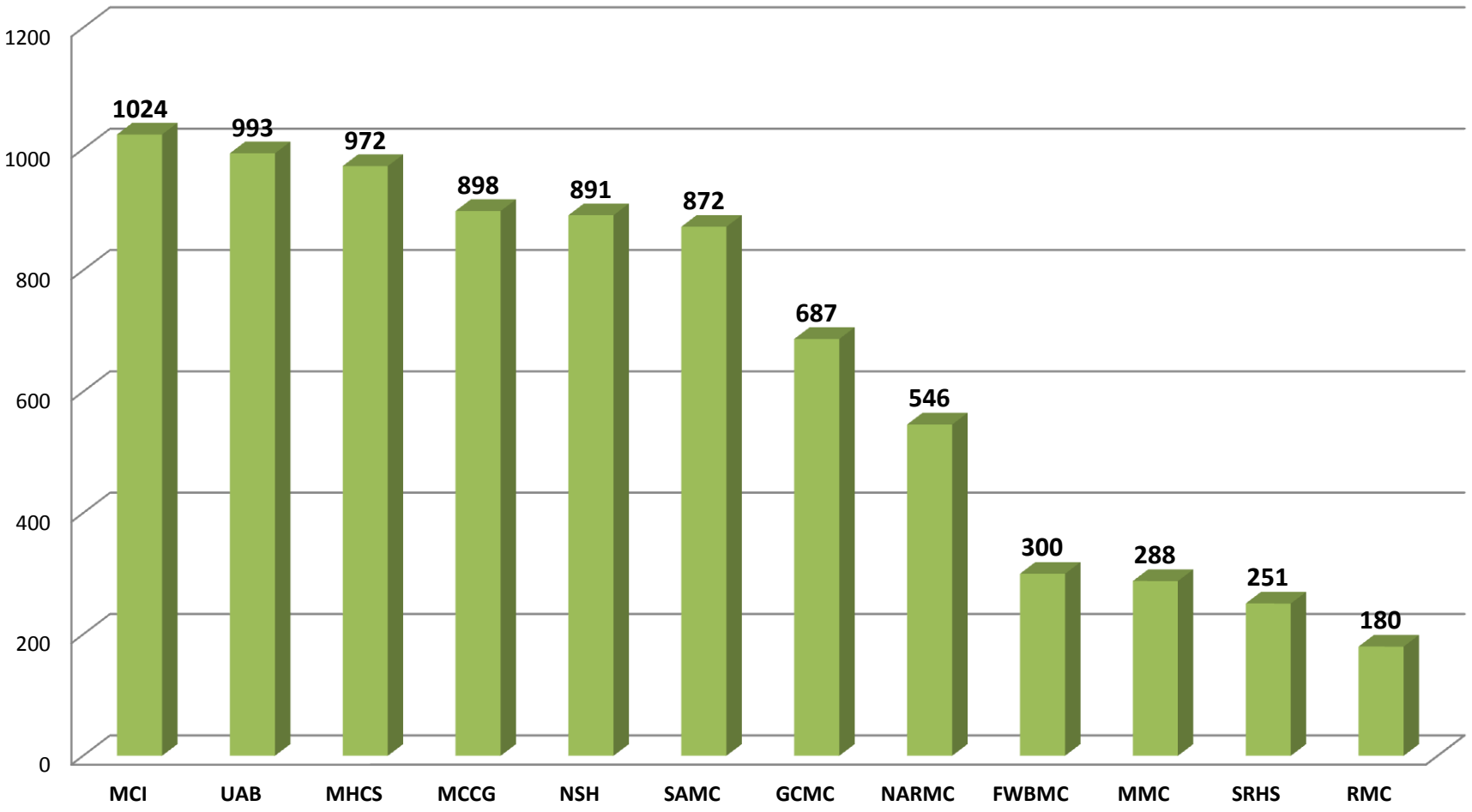
Patients Characteristics (n = 4583)	
	All Sites
Sex (%)	
Female	47.0%
Male	53.0%
Age (%)	
65-74	45.1%
75-84	30.7%
85+	7.6%
Race (%)	
Caucasian	87.0%
African American/ Black	11.9%
Comorbidities (%)	
None	18.7%
1	11.7%
2-3	28.8%
3+	24.1%

52.9%

Patient Characteristics

Education	
	All Sites (n = 694)
College 4 years or more (College graduate)	20.6%
College 1 year to 3 years (Some college or technical school)	14.1%
Grade 12 or GED (High School graduate)	31.6%
Grades 9 through 11 (Some High School)	11.8%
Grades 1 through 8 (Elementary)	4.2%
Refused	15.1%
Don't Know/Not Sure	2.6%

PCC Patients by Site



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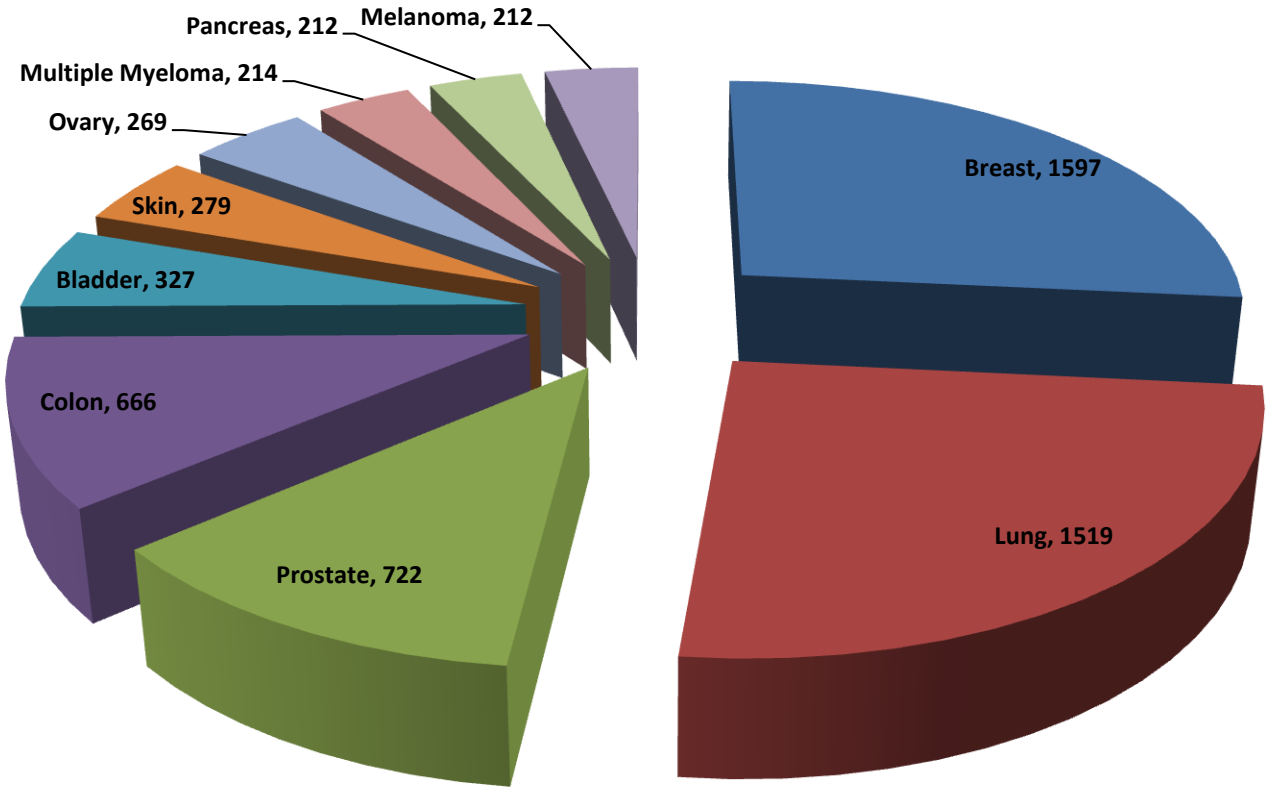
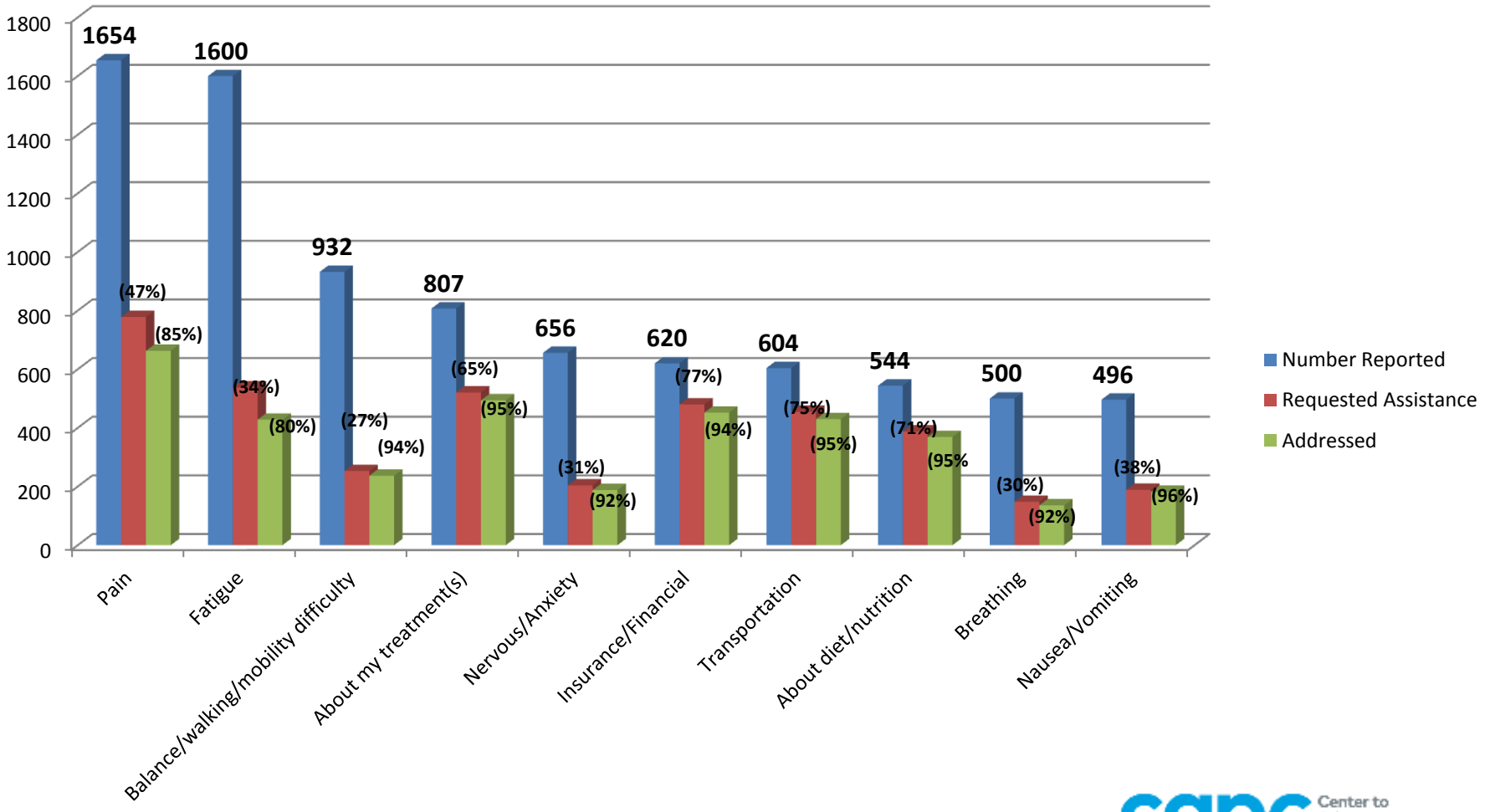
PCC Patients by Diagnosis



Top 10 Distress Items Reported



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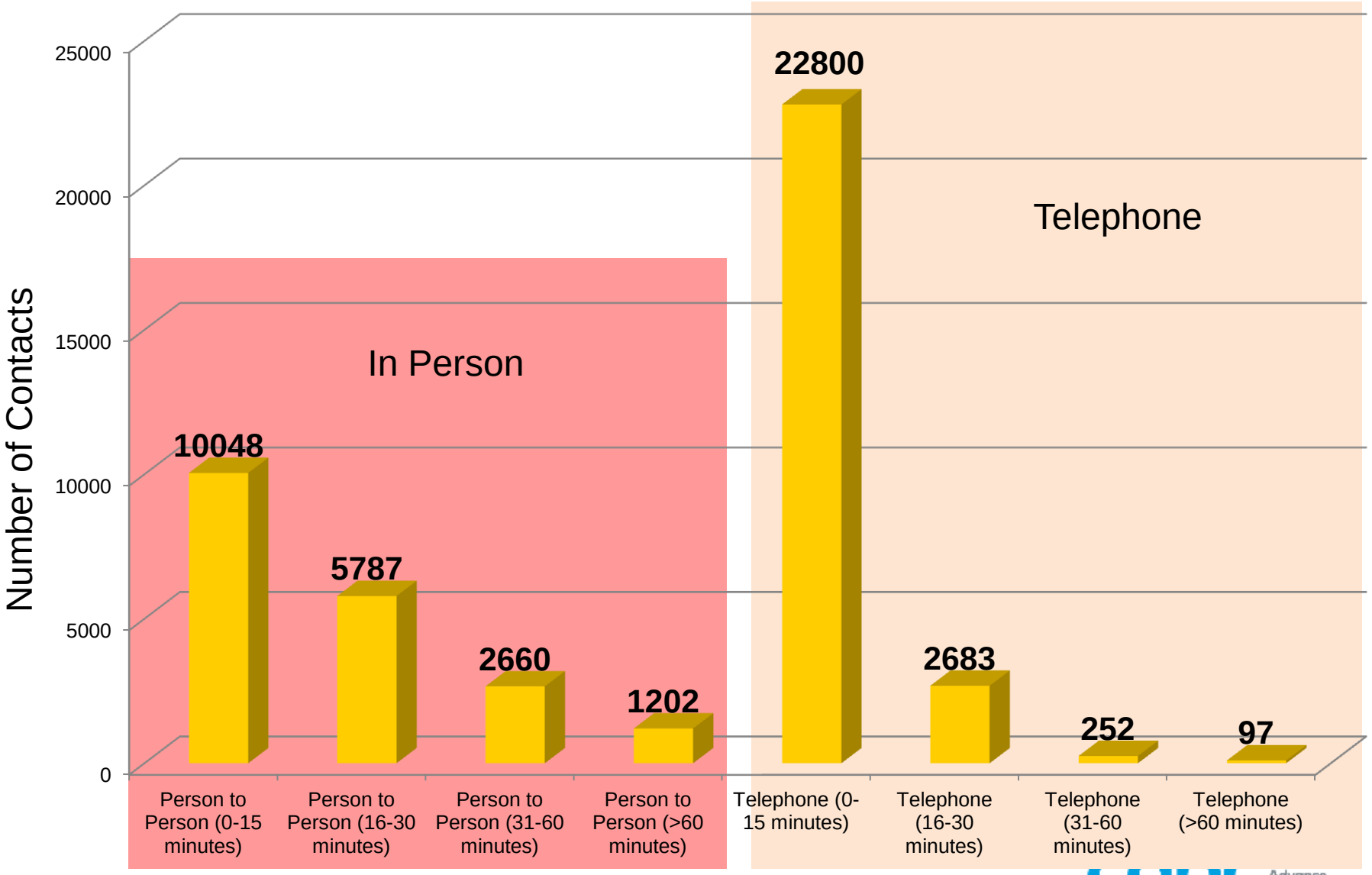
Navigation Activities: Distress Assessment

- 2,951 Distress Assessments administered
- 1,904 Barriers identified (533 acute)
  - Time to resolve barriers 16.6 days → 2.3 days
- 79.6% of barriers have been resolved

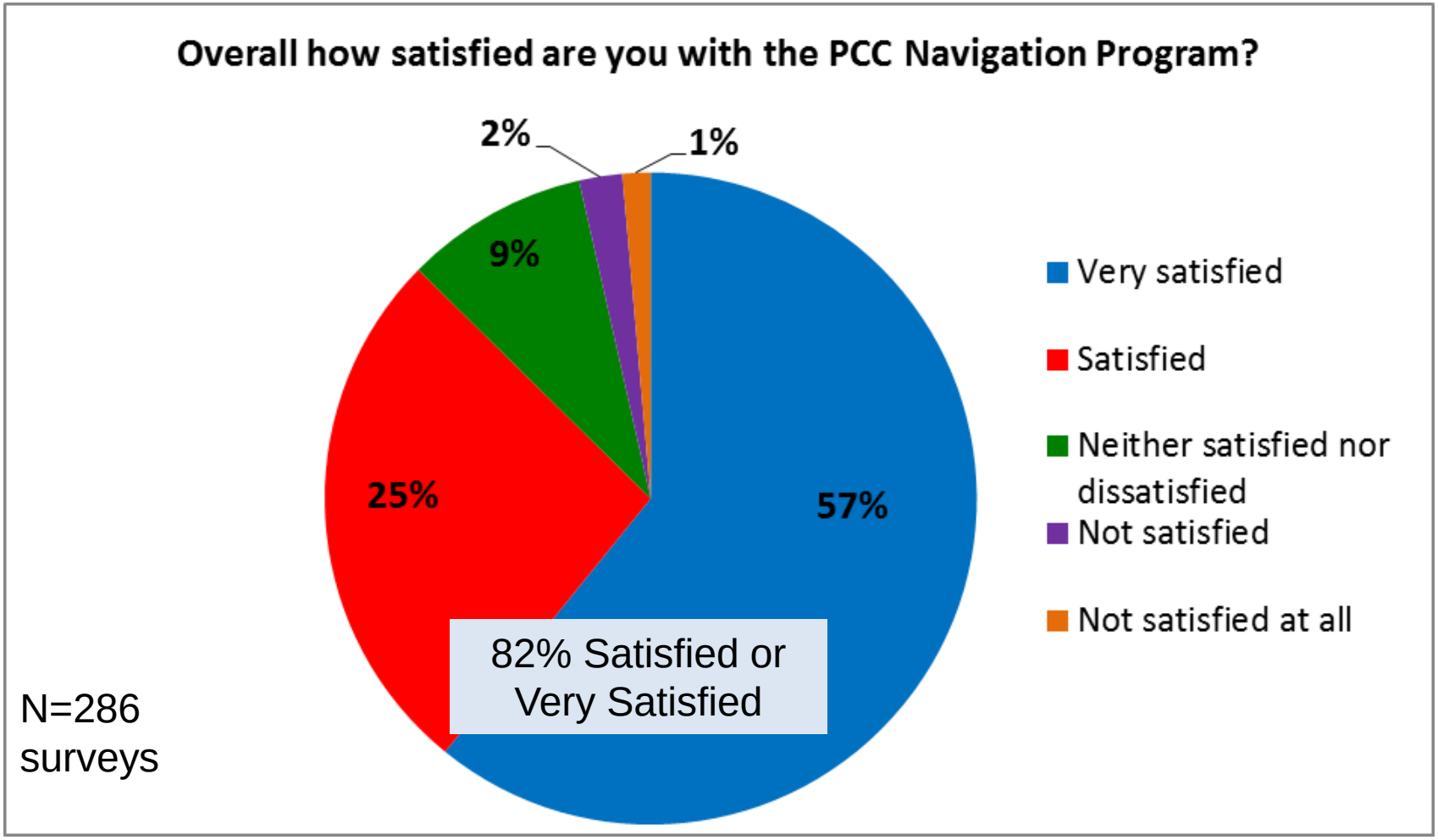
PCC Patient Contacts



Navigator Activities

- Average Number of:
  - Patients per navigator = 99.6
  - Active Patients per navigator = 78.8
    - 72.9% of patients are active
  - High acuity patients per navigator = 63.1

Patient Satisfaction



Resource Utilization Trends

Resource Utilization

- Consistent positive trends on health care utilization
  - Reduction of ER visits, hospitalization
  - Reduction in ICU stays
  - Increased hospice utilization
  - Overall cost reduction that exceeded our predicted modeled savings

Challenges and Surprises

1. Completion of UAB leadership team
   - Challenges and surprises:
     - ➢IRB process for community sites
     - ➢Need for physician engagement
2. Onboarding of associate sites
   - Challenges and surprises:
     - ➢Turnover early in the program (3 navigator positions replaced over 6 months)

Challenges and Surprises

3. Building strong relationships with associate sites
    - Challenges and surprises:
        - Technology challenges across all sites
        - Underappreciated physician time
4. Training of all navigators
    - Challenges and surprises:
        - Surprised by the difficulties encounter in training lay population
        - Underestimated the impact of the variability of navigator experience and baseline knowledge

Challenges and Surprises

5. Collaboration with navigation software vendor

- Challenges and surprises:
  - ➢Ongoing system modification

Challenges and Surprises

6. Self Monitoring:
    - Evaluation of navigation process and utilization of system tools
    - Evaluate methods for enrollment
    - Obtain comparison data; the most difficult aspect of this project

Communication from Navigator Team

- Access to medical records
- Notes from Navigators can be printed and scanned
- Direct contact with treating team

Additional Feedback from Navigators

- Patients have requested improved communication
  - About test results
  - Prognosis
- Interest in same-day urgent clinic visits rather then being sent to the ER
  - Process Discussion

Thank You!

Contact Information:

- Marie Bakitas mbakitas@uab.edu

- Elizabeth Kvale ekvale@uabmc.edu

Questions and Comments

- Do you have questions for the presenter?

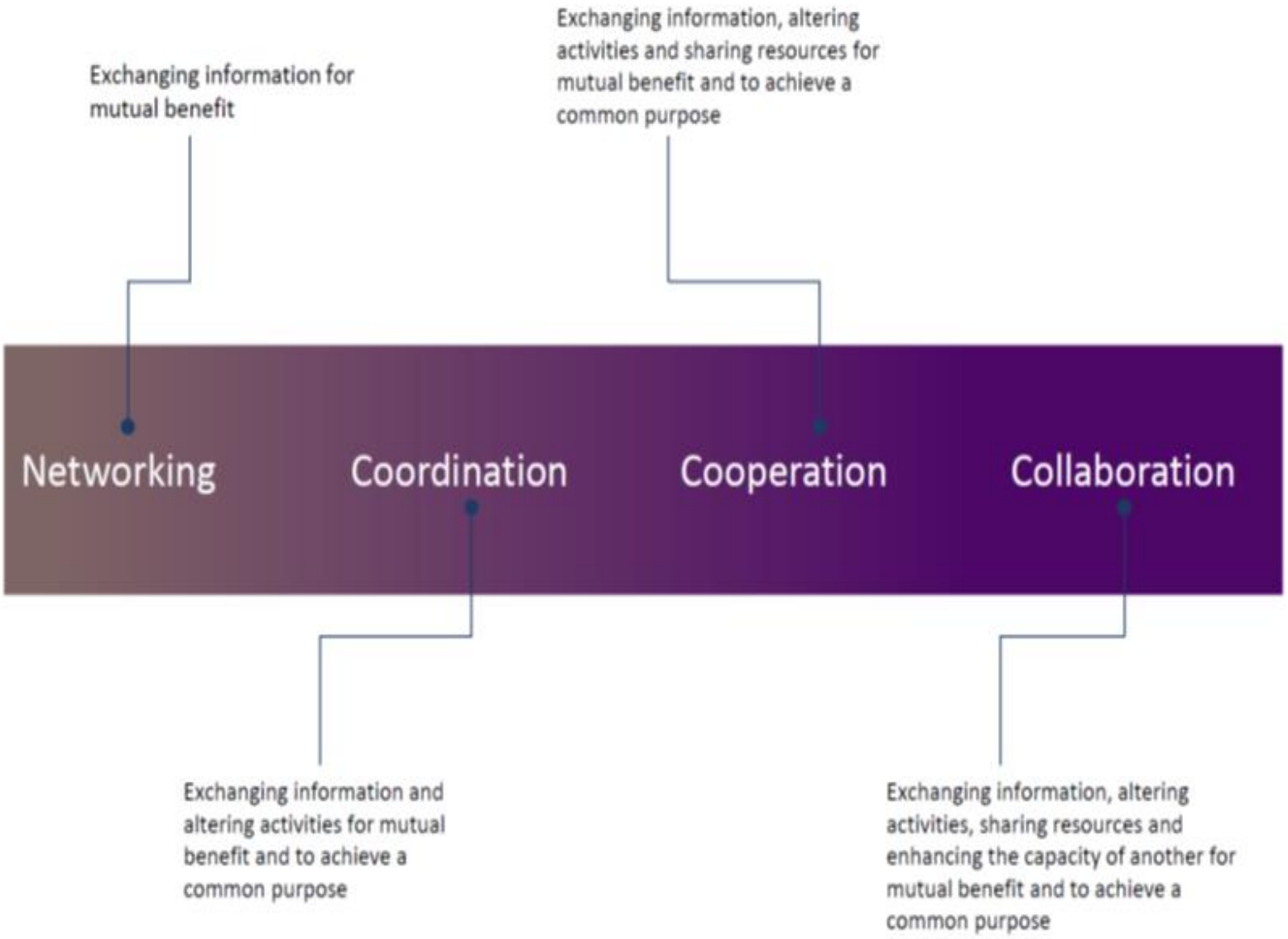
- Click the hand-raise icon on your control panel to ask a question out loud, or type your question into the chat box.

CAPC Events and Webinar Recording

- For a calendar of CAPC events, including upcoming webinars and office hours, visit
  - https://www.capc.org/providers/webinars-and-virtual-office-hours/

- Today's webinar recording can be found in CAPC Central under **'Webinars: Community-based Palliative Care'**
  - https://central.capc.org/eco_player.php?id=186

Figure 1. Types of Population Health Partnerships



Source: Adapted from Robert Pestronk's Collaborating for Healthy Communities *and Arthur T. Himmelman's* Collaboration for a Change: Definitions, Decision-making Models, Roles and Collaboration Process Guide, *2013.*[1]

Characteristics of E2

	ENABLE 2	ENABLE 3
STUDY DATES	Nov 2003-May 2008	Oct 2010-March 2013
SAMPLE	N=322	N=207
CANCER SITES	New dx, recurrence, progression- Lung, GI, GU, Breast	New dx, recurrence, progression- Lung, GI, GU, Breast, other solid tumors & Heme
COMPARISON GROUPS	Early PC vs Usual Care	Early PC vs Delayed PC (12 weeks)
TELE-HEALTH INTERVENTION	In-person PC consult followed by 4 Patient sessions & monthly phone f/u & bereavement call	In-person PC consult followed by 6 Patient & 3 Caregiver sessions & monthly phone f/u till death & bereavement call
OUTCOME MEASURES	QOL (FACIT-pal) Sx Intensity (ESAS) Mood (CES-D) Resource Use Afterdeath Interview Survival (post hoc)	QOL (FACIT-pal) Sx Impact (QUAL-E) Mood (CES-D) Survival Resource Use Care Quality (PACIC) & QODD
RESULTS	Improved QOL, mood, Trends Sx intensity, Survival Similar Resource use	PT Outcomes - Similar QOL, Mood, Sx Impact, & Resource Use Improved Survival CG Outcomes- Improved QOL, Burden, Depression

The ENABLE II RCT: What did we do?

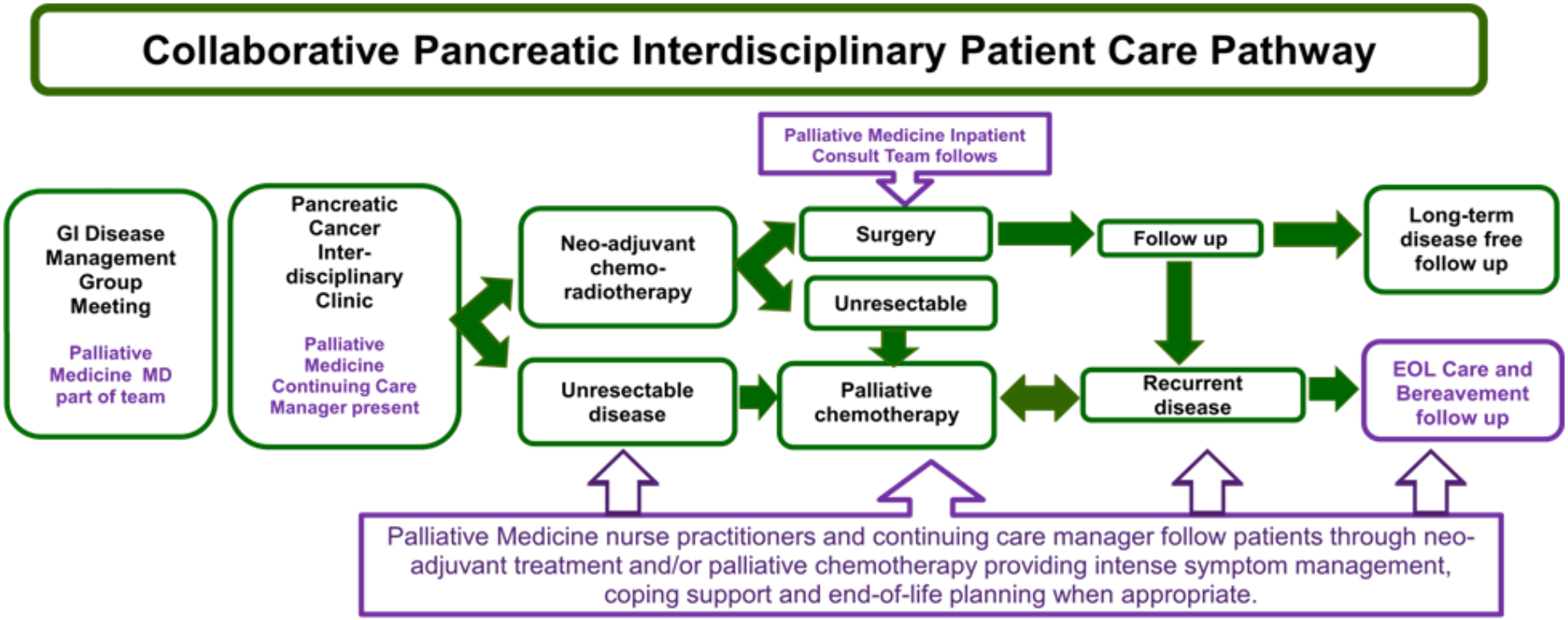
Intervention

- Early Identification via ‘tumor board’
- In-Person Palliative Care Assessment
- Palliative care nurse coach/care coordinator
  - Phone-based intensive curriculum “Charting your Course”
  - Monthly contact for referral/care coordination
- Shared Medical Appointments

Usual Care

- Regular oncology clinician appointments
- Access to (newly-developed) Palliative Consult Team & Supportive Care Services

What were our Results?



©Caron, P., Bakitas, M. (with permission)

Bakitas M, Bishop MF, Caron P, Stephens L. Developing successful models of cancer palliative care services. *Semin Oncol Nurs.* Nov 2010;26(4):266-284.

ENABLE "Lessons Learned"

- Caregivers REALLY need individual attention
- Stay flexible
- Patients learned about communication with clinicians; therefore nurse coach communication with team not necessary
- Concerns about establishing rapport and doing assessment via phone unfounded
- Patients worried about not being 'loyal' to primary clinicians

ENABLE Challenges

- Timing: Is it ever too early?
  - *"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)"*
- Getting non-palliative care clinician buy-in
- Economic analysis is needed
- Still need to determine mechanism

“I am only one; but still I am one. I cannot do everything; but still I can do something; and because I cannot do everything, I will not refuse to do the something that I can do.”

Statement published in A Year of Beautiful Thoughts (1902) by Jeanie Ashley Bates Greenough

National Cancer Institute

Research-tested Intervention Programs (RTIPs)

http://rtips.cancer.gov/rtips/

RTIPs – Moving Science into Programs for People

Research-tested Intervention Programs (RTIPs) is a searchable database of cancer control interventions and program materials and is designed to provide program planners and public health practitioners easy and immediate access to research-tested materials. Sponsored by the National Cancer Institute (NCI) and the Substance Abuse and Mental Health Services Administration (SAMHSA), the online directory provides a review of programs available for use in a community or clinical setting.

Key Features

- Full program summaries, including 'About the Study' section, program scoring, and related publications.
- Interventions that have been reviewed by an expert panel and associated program materials that are available at no cost on CD-ROM or through dissemination by the developer.
- *Using What Works*: This online set of guidelines, developed by NCI, illustrates how to adapt or tailor a program while maintaining the integrity of the research.
- Links to the *Guide to Community Preventive Services* that provide recommendations for intervention approaches that promote population health.