Enhancing Access to Rural Palliative Care

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Center for Palliative and Supportive Care
UAB | The University of Alabama at Birmingham
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

Metro and nonmetro counties, 2013

Source: USDA, Economic Research Service using data from the U.S. Census Bureau.
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 Hospice and Palliative Care

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)
Barriers/Challenges to Rural Palliative Care

→ **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)

“...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
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

_Educate, Nurture, Advise, 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_
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

PROMOTING EXCELLENCE IN END-OF-LIFE CARE

A NATIONAL PROGRAM OF THE ROBERT WOOD JOHNSON FOUNDATION
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**

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

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(Removed July 5, 2008; Accepted October 10, 2008)

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LOOKING AHEAD
Choices for medical care when you’re seriously ill
Ottawa Personal Decision Guide

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 both the benefits and risks of each option?
☒ No  ☒ Yes

Values: Are you clear about which benefits and risks matter most to you?
☒ No  ☒ Yes

---

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.’

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

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

*But only half of participants could get to in-person sessions*
60% of patients served were “rural”
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

A. Primary Care

B. Oncology Care

C. Palliative Care

D. Other Specialists: Pain Service, GI, Rad. Onc, Surgery

- Patient Activation
- Delivery System / Decision Support
- Problem-solving/Contextual Counseling
- Follow-up/Coordination
- Goal Setting

E. Hospice & Bereavement Care

Goals of phone-based palliative nurse coaching
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

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.
What were our Results?

Kaplan–Meier Estimates of Survival According to Study Group


What were our Results?
What were our Results?

No. at Risk

<table>
<thead>
<tr>
<th></th>
<th>Immediate</th>
<th>Delayed</th>
</tr>
</thead>
<tbody>
<tr>
<td>104</td>
<td>98</td>
<td>89</td>
</tr>
<tr>
<td>103</td>
<td>83</td>
<td>73</td>
</tr>
</tbody>
</table>

\[ P = 0.038 \]
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)
Project ENABLE II

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 half a 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)

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 ...

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 additional, the steps needed to carry out the research-tested program, relevant program...
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
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

Prevention → Early Detection → Evaluation & Treatment Planning → Active Treatment → Post Tx Follow Up → Survivorship & Surveillance → Palliative & Hospice

First 12 Months

Community Coordinator (Recruitment & Awareness)

CMS Patient Navigators (Non-Nurse)

Advanced Disease

Diet & Exercise
Age Appropriate Screening
Prompt Evaluation
Accurate Diagnosis
Complete Treatments
Stay on Medications
Regular Surveillance
Physical Activity / Healthy Diet

Tobacco Control
Risk Management
Accurate Treatment Plan
Clinical Trials
Stay on Medications
Manage Comorbidities
Manage Comorbidities

Risk Management

Complete Treatments
Stay on Medications

Early Detection
Evidence Based Treatment Plan
Avoid unnecessary ED visits & Hospital stays
Avoid unnecessary ED visits & Hospital stays
Avoid unnecessary ED visits & Hospital stays

Prevention of Disease
Reduced Cost

Focus

Savings

Avoid ED visits & Hospital stays
Reduce cost for Advanced Disease care
Eligibility Criteria

➔ Medicare Patient
  – Primary A and/or B

➔ Age ≥ 65

➔ Cancer Diagnosis
  – Pathology required
Navigation Teams

Leadership Team

- Program Manager
  - Admin. Support
- Director of Nursing
- Navigation Team
- Training Manager
- Financial Officer
- Marketing Specialist
  - Community Education
- Data Mgr / Reporting
  - Data Entry

Affiliate Site

- Medical Director (MD)
- Program Manager (RN)
  - Lay Navigator (non-nurse)
  - Lay Navigator (non-nurse)
  - Lay Navigator (non-nurse)

Patient Encounter Software System

Medical Concierge: Navigator
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 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

Adapted with permission from the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Distress Management V.2.2013. © 2013 National Comprehensive Cancer Network, Inc. All rights reserved.
SAMPLE

Knowledge Deficit of ____ V1.22.13

New Condition, Tx, etc.
Decreased Knowledge of: ___

Assessment
Knowledge level?

Intervention
Plan

Evaluation
Goal / Intervention

Resolved
Document in Software:
Date
Close barrier

NOT Resolved
Document in Software

Repeat:
- Assessment
- Plan
- Intervention
- Evaluation

Resolved
Document in Software:
Date
Close barrier

NOT Resolved
Document in Software

Repeat:
- Assessment
- Plan
- Intervention
- Evaluation

Implement new plan and evaluate
Consult with SM and/or LN team members for input and modification of Care Plan

NOT Resolved

CONFIDENTIAL CONTENT. PROPERTY OF UAB MEDICINE
**Navigation Software**

**PATIENT CARE CONNECT**
University of Alabama at Birmingham

- **Pri Diag:** Lung
- **DOB:** 03/30/1947
- **Age:** 67 years
- **Gender:** Male
- **MRN:** [obscured]
- **Alt Status:** CMS - High Acuity

**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

**Contacts**

<table>
<thead>
<tr>
<th>Contact Type</th>
<th>Contact Reason</th>
<th>Contact Date</th>
<th>Note/Document</th>
</tr>
</thead>
<tbody>
<tr>
<td>General</td>
<td></td>
<td>11/11/2014 at 04:01PM</td>
<td>Return appt in outlook</td>
</tr>
<tr>
<td>Telephone (0-15 minutes)</td>
<td></td>
<td>11/07/2014 at 03:26PM</td>
<td>Mr. [obscured] called to report that he wants to see an endocrinologist; he really feels like he has issues going on with thyroid. see DT</td>
</tr>
<tr>
<td>Telephone (0-15 minutes)</td>
<td>Follow-Up</td>
<td>10/28/2014 at 03:29PM</td>
<td>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.</td>
</tr>
<tr>
<td>Letter</td>
<td></td>
<td>09/04/2014 at 04:28PM</td>
<td>Mailed brochures about patient portal to patient.</td>
</tr>
<tr>
<td>Email</td>
<td></td>
<td>09/04/2014 at 04:28PM</td>
<td>Emailed link, phone numbers, etc. about UAB Patient portal.</td>
</tr>
<tr>
<td>Telephone (0-15 minutes)</td>
<td></td>
<td>09/04/2014 at 04:27PM</td>
<td>F/U call to Mr. [obscured]; he is wanting more information on the patient portal for his sister who is also a cancer patient; I told him I would send brochures.</td>
</tr>
<tr>
<td>Person to Person (0-15 minutes)</td>
<td></td>
<td>09/03/2014 at 04:52PM</td>
<td>Initial phone intro as assigned patient navigator; overall feeling well; chemo has really helped; question about patient portal-- does it show appointment dates?</td>
</tr>
<tr>
<td>Letter</td>
<td></td>
<td>08/05/2014 at 05:14PM</td>
<td>Mailed intro letter</td>
</tr>
<tr>
<td>General</td>
<td></td>
<td>08/05/2014 at 05:13PM</td>
<td>Entered demographics and appt info into system</td>
</tr>
</tbody>
</table>
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
# Patient Characteristics

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

The data presented is confidential, unpublished information. Do not share without permission from UAB Patient Care Connect Coordinating Center. Contact 205-996-7731.
# Patient Characteristics

<table>
<thead>
<tr>
<th>Education</th>
<th>All Sites (n = 694)</th>
</tr>
</thead>
<tbody>
<tr>
<td>College 4 years or more (College graduate)</td>
<td>20.6%</td>
</tr>
<tr>
<td>College 1 year to 3 years (Some college or technical school)</td>
<td>14.1%</td>
</tr>
<tr>
<td>Grade 12 or GED (High School graduate)</td>
<td>31.6%</td>
</tr>
<tr>
<td>Grades 9 through 11 (Some High School)</td>
<td>11.8%</td>
</tr>
<tr>
<td>Grades 1 through 8 (Elementary)</td>
<td>4.2%</td>
</tr>
<tr>
<td>Refused</td>
<td>15.1%</td>
</tr>
<tr>
<td>Don’t Know/Not Sure</td>
<td>2.6%</td>
</tr>
</tbody>
</table>
PCC Patients by Site

- MCI: 1024
- UAB: 993
- MHCS: 972
- MCCG: 898
- NSH: 891
- SAMC: 872
- GCMC: 687
- NARMC: 546
- FWBMC: 300
- MMC: 288
- SRHS: 251
- RMC: 180
Top 10 Distress Items Reported

- Pain: 1654 (85%), 1600 (84%), 932 (27%), 807 (94%), 656 (92%), 620 (94%), 604 (95%), 544 (95%), 500 (92%), 496 (96%)
- Fatigue: 1600 (95%), 932 (94%), 807 (91%), 656 (97%), 620 (77%), 604 (31%), 544 (38%), 500 (30%), 496 (96%)
- Balance/walking/mobility difficulty: 807 (95%), 932 (94%), 656 (95%), 620 (95%), 604 (95%), 544 (95%), 500 (92%), 496 (96%)
- About my treatment(s): 807 (55%), 932 (27%), 656 (92%), 620 (94%), 604 (95%), 544 (95%), 500 (92%), 496 (96%)
- Nervous/Anxiety: 807 (95%), 932 (94%), 656 (95%), 620 (94%), 604 (95%), 544 (95%), 500 (92%), 496 (96%)
- Insurance/Financial: 807 (95%), 932 (94%), 656 (95%), 620 (94%), 604 (95%), 544 (95%), 500 (92%), 496 (96%)
- Transportation: 807 (95%), 932 (94%), 656 (95%), 620 (94%), 604 (95%), 544 (95%), 500 (92%), 496 (96%)
- About diet/nutrition: 807 (95%), 932 (94%), 656 (95%), 620 (94%), 604 (95%), 544 (95%), 500 (92%), 496 (96%)
- Breathing: 807 (95%), 932 (94%), 656 (95%), 620 (94%), 604 (95%), 544 (95%), 500 (92%), 496 (96%)
- Nausea/Vomiting: 807 (95%), 932 (94%), 656 (95%), 620 (94%), 604 (95%), 544 (95%), 500 (92%), 496 (96%)

Note: The numbers in parentheses represent the percentage of cases for which assistance was requested and addressed.
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
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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

Overall how satisfied are you with the PCC Navigation Program?

- Very satisfied: 57%
- Satisfied: 25%
- Neither satisfied nor dissatisfied: 9%
- Not satisfied: 2%
- Not satisfied at all: 1%

N=286 surveys

82% Satisfied or Very Satisfied

(N=286 surveys, Patient Satisfaction: 82% Satisfied or Very Satisfied)
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 encountered 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:

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➔ 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

➔ Today’s webinar recording can be found in CAPC Central under ‘Webinars: Community-based Palliative Care’
Figure 1. Types of Population Health Partnerships

Exchanging information for mutual benefit

Exchanging information and altering activities for mutual benefit and to achieve a common purpose

Exchanging information, altering activities and sharing resources for mutual benefit and to achieve a common purpose

Exchanging information, altering activities, sharing resources and enhancing the capacity of another for mutual benefit and to achieve a common purpose

Networking  Coordination  Cooperation  Collaboration

## Characteristics of E2

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

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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
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.