McGill Palliative Care
National Grand Rounds
2025 Series

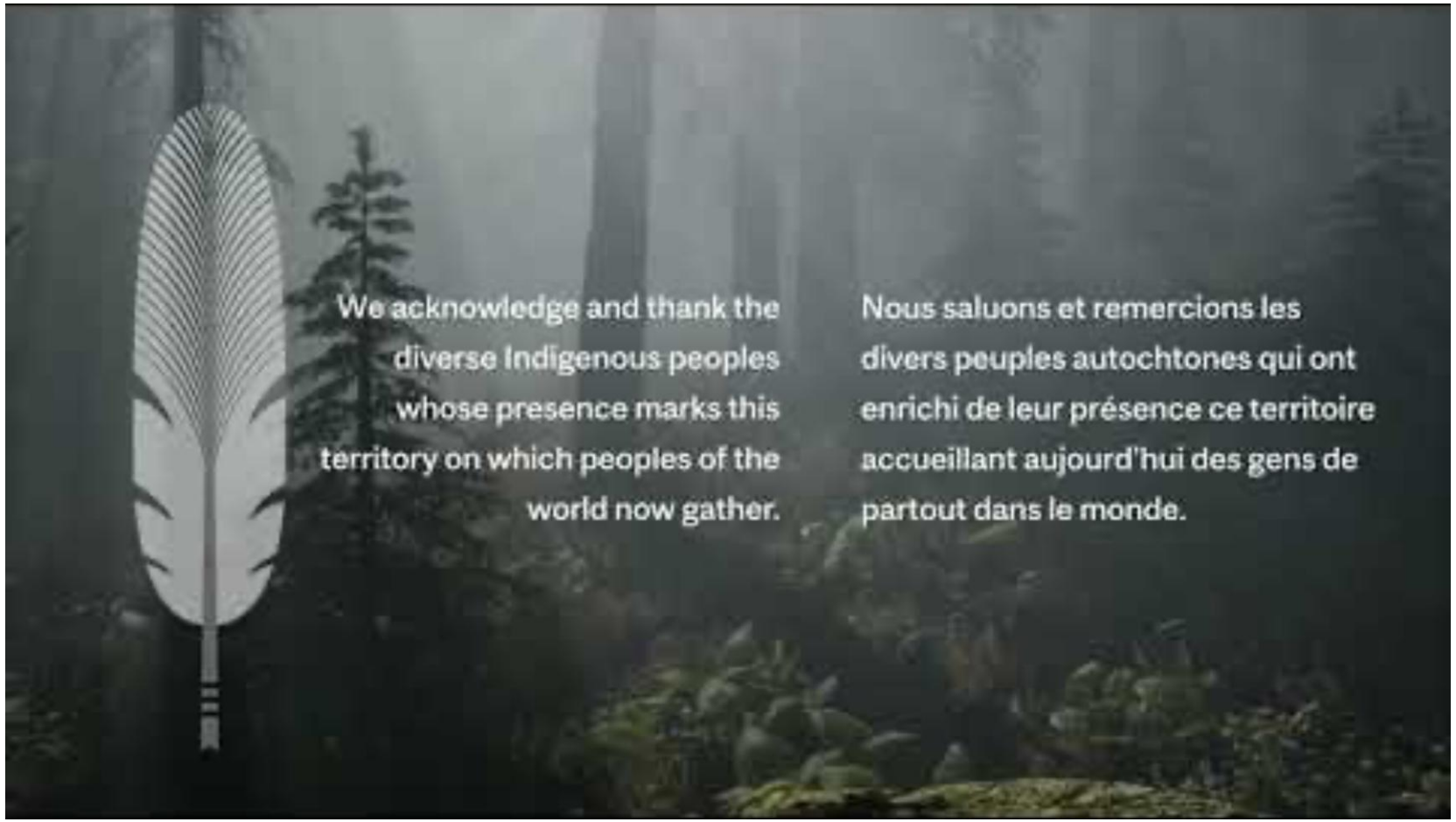
MCGILL
SOINS PALLIATIFS

MCGILL
PALLIATIVE CARE

Project ECHO
Palliative Care - Canada

BY

Pallium Canada


We acknowledge and thank the diverse Indigenous peoples whose presence marks this territory on which peoples of the world now gather.
Nous saluons et remercions les divers peuples autochtones qui ont enrichi de leur présence ce territoire accueillant aujourd'hui des gens de partout dans le monde.

Scientific Planning Committee

Justin Sanders
Chair

Stéfanie Gingras
Course Director

Zelda Freitas

Naomi Goloff

Olivia Nguyen

Orel Shuker

Argerie Tsimicalis

Janel Walsh

Conflict of Interest Declarations
Scientific Planning Committee Members

Name	Advisory Board or Committee	Honoraria or Grants
Justin Sanders, MD, MSc, FAAHPM	Maison St-Raphaël (Palliative Care Residence), American Society for Clinical Oncology (Guideline Committee)	Oklahoma University Health Sciences (honorarium), Oregon Health Sciences University (honorarium), Pancreatic Cancer Canada (grant)
Stéfanie Gingras, MD, CCFP, FCFP, CAC-PC	None	None
Zelda Freitas BA, BSW, MSW, TS	McGill Council on Palliative Care, NOVA Montreal, Canadian Centre for Caregiving Excellence	Center for Caregiving Excellence for the Caregiver Grief Connection Project (Azreli Foundation grant)
Naomi Goloff, MD, FRCPC, FAAHPM	Canadian Society of Palliative Medicine, ALPM pediatric representative	Kindred Foundation and AQSP (grants)
Olivia Nguyen MD, MM, CCMF(SP), FCMF, FRCPC	Société québécoise des médecins de soins palliatifs	Chaire de la famille Blanchard pour l'enseignement de la recherche en soins palliatifs (Research subvention)
Orel Shukar, MD	None	None
Argerie Tsimicalis, RN, PhD	None	None
Janel Marie Walsh, MD, CFPC	None	None

Disclosure of Financial Support for Overall Program

This program has received unrestricted educational grants from:

- *Cedars Cancer Foundation*
- *Hope & Cope Wellness Center*
- *Jewish General Hospital Foundation*
- *Montreal General Hospital Foundation*
- *Montreal Neurological Institute*
- *MUHC Foundation*
- *Pallium Canada*
- *St. Mary's Hospital Foundation*
- *Montreal Institute for Palliative Care, a branch of the Teresa Dellar Palliative Care Residence*
- *The Montreal Children's Hospital Foundation*

Special thanks to the Department of Family Medicine at McGill University for in-kind support.

McGill | Department of Family Medicine

Mitigation of Potential Bias

Strategies discussed by the scientific planning committee (SPC) to manage or mitigate the identified potential sources of bias prior to or during the CPD (Continuous Professional Development) activity.

- Potential conflicts of interest for every member of the SPC is listed in writing at the start of the presentation.
- All speakers will disclose potential conflicts of interest in writing and verbally at the time they present.
- The Chair is responsible for reviewing all content prior to presentation. Should a conflict be identified, the Chair (alone or with consultation with the SPC) will ask for the removal or reworking of that content in order to mitigate any bias.
- The Chair has also reviewed all the Conflict-of-Interest forms for the SPC and the speakers and is thus fully informed as to their status.

Overall Program Learning Objectives

- Review innovative approaches for the implementation of palliative care in different settings
- Assess strategies to address the most important challenges in palliative care today
- Appraise the latest research in the field of palliative care

McGill Palliative Care
National Grand Rounds
2025 Series

Palliative Care McGill National Grand Rounds Lecture

Marie Anne Bakitas, DNSc, NP-C (ret.), AOCN, ACHPN, FPCN, FAAN

October 15, 2025

MCGILL SOINS PALLIATIFS MCGILL PALLIATIVE CARE

Project ECHO Palliative Care - Canada BY Pallium Canada

Conflict of Interest Declaration

Marie Anne Bakitas, DNSc, NP-C (ret.), AOCN, ACHPN, FPCN, FAAN

I have/had an affiliation (financial or otherwise) with a for-profit/not-for-profit organization.

- I am a member of the National Clinical Scholars Program (USA), Jan 2023-present

I have received grants/honoraria from a for-profit/not-for-profit organization

- National Institute of Health (USA), 2007 to present

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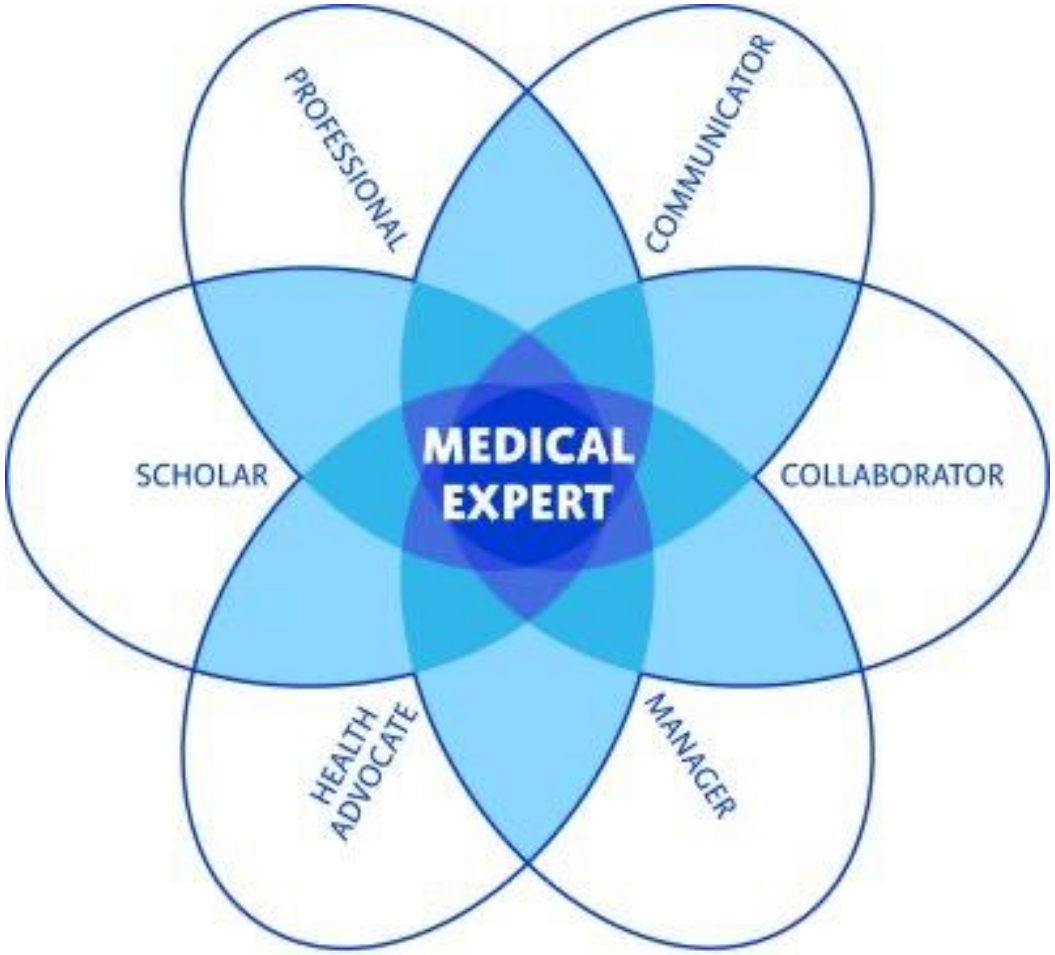
The CanMED competencies that will be identified during this presentation:

- Scholar
- Health Advocate
- Professional



Unmuting Rural Voices: Towards Health Equity in Palliative Care

McGill

Learning Objectives

- Recognize how the triple threat of rurality, age, and race combine to create disparities in palliative care access.
- Consider community-informed approaches that can enhance rural palliative care access and acceptability.
- Discuss strategies to implement culturally-based palliative care models.

Unmuting Rural Voices: Towards Health Equity in Palliative Care

McGILL SOINS PALLIATIFS | McGILL PALLIATIVE CARE

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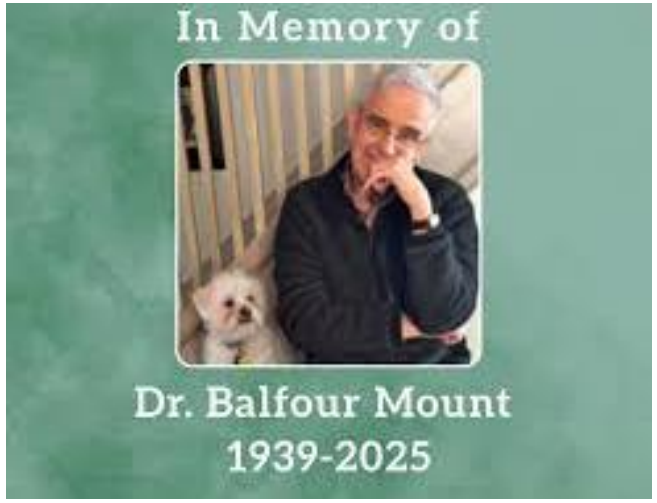
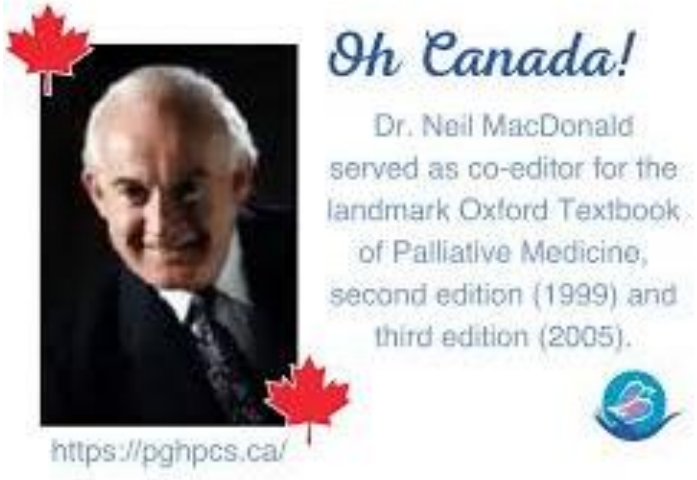
McGill

Marie Bakitas, DNSc, CRNP, FAAN
Associate Director, UAB Center for Palliative & Supportive Care
University of Alabama at Birmingham

McGill Palliative Care
National Grand Rounds
October 15, 2025

My Canadian Palliative Care Heros





Dr. Camilla Zimmermann

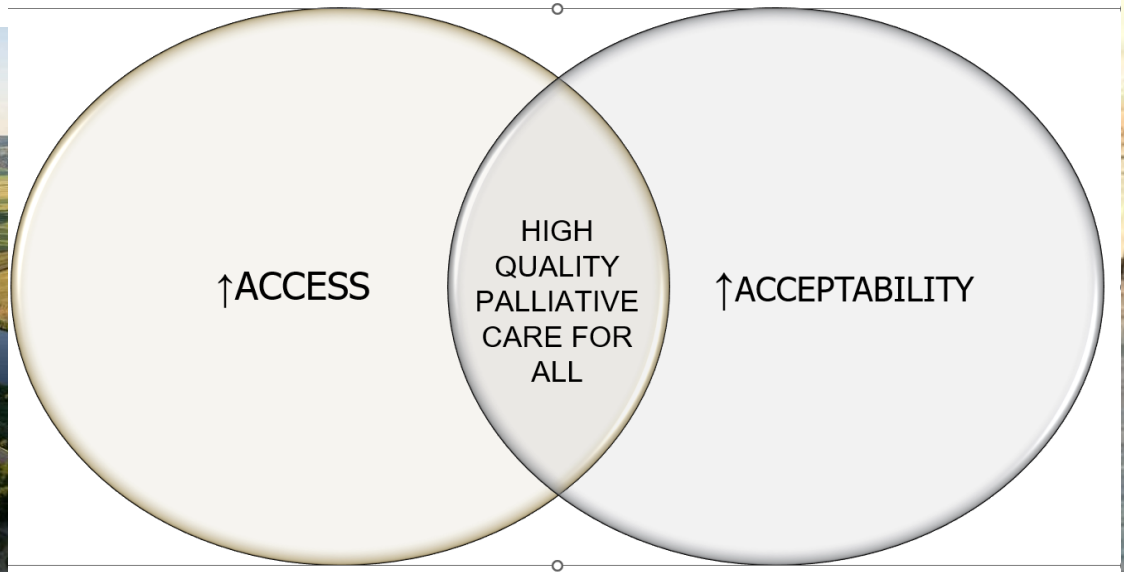
Dr. Justin Sanders

Take Home Messages

- Rural palliative care inequities result from a 'perfect storm' of older, sicker, poorer populations, medical mistrust, & few healthcare & palliative care resources.
- Realizing equitable, effective, & sustainable rural palliative care requires:

*increasing access

*culturally adapting care



Maebel's Story

- Maebel is 78 yo African American woman with newly diagnosed glioblastoma discovered after a tonic-clonic seizure at home.

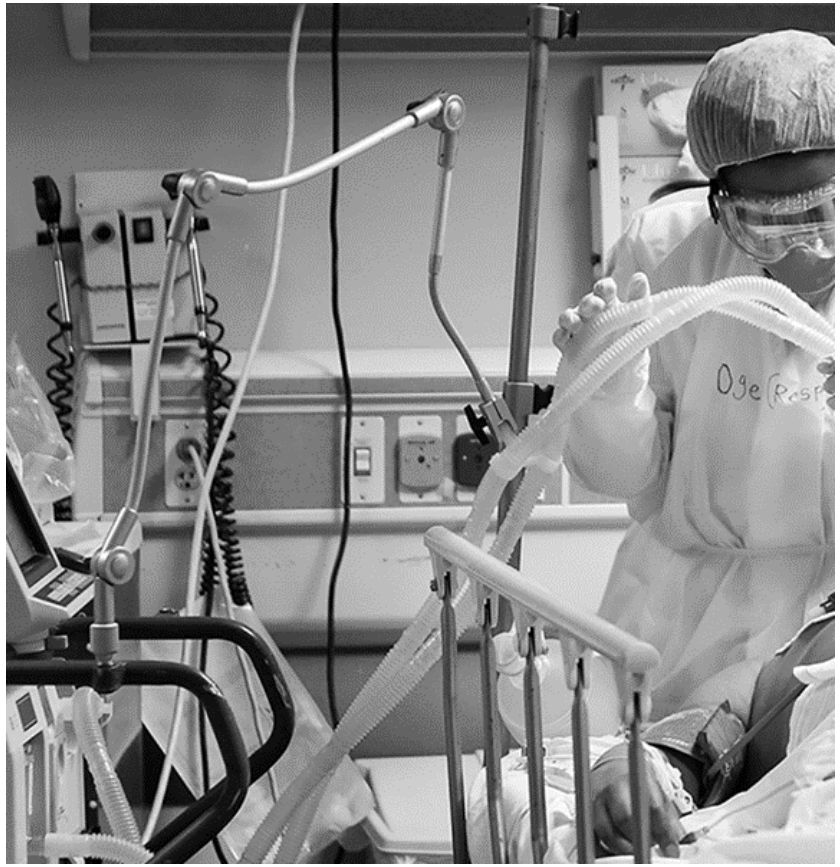
- She lives in rural Alabama, is a devout Baptist, widow, with 5 children, 10 grandchildren, & 3 great-grandchildren-- all but 1 live hours away in "the city".

- Her GP refers her to the comprehensive cancer center 50 miles away. Her family believes she will receive better care there.

- The academic oncologist recommends palliative radiation and chemo for inoperable tumor. She returns home to pray and discuss with her family.

Maebel's Story

- Within a week of returning home, she develops headache and vomiting.
- She goes to the local rural hospital ED and is airlifted to the cancer center.
- Maebel assents to recommended 'palliative' XRT because she is told it will make her "feel better".
- Family unable to visit due to transportation and work issues.
- After a few days she becomes febrile, confused & experiences respiratory distress.
- During a lengthy resuscitation effort, MDs attempt to contact family to understand her wishes for life-sustaining treatments... She dies alone.



Maebel's Journey

Tertiary Hospital / Cancer Center

Home

Emergency Department

Rural Healthcare

Tertiary Hospital/ Cancer Center

Home-health

? Hospice

WHERE IS PALLIATIVE CARE?

Objectives

Review rural characteristics that create disparities in palliative care.

Consider approaches that can enhance access & acceptability

Discuss strategies to implement culturally-based palliative care.

Objectives

Review rural characteristics that create disparities in palliative care.

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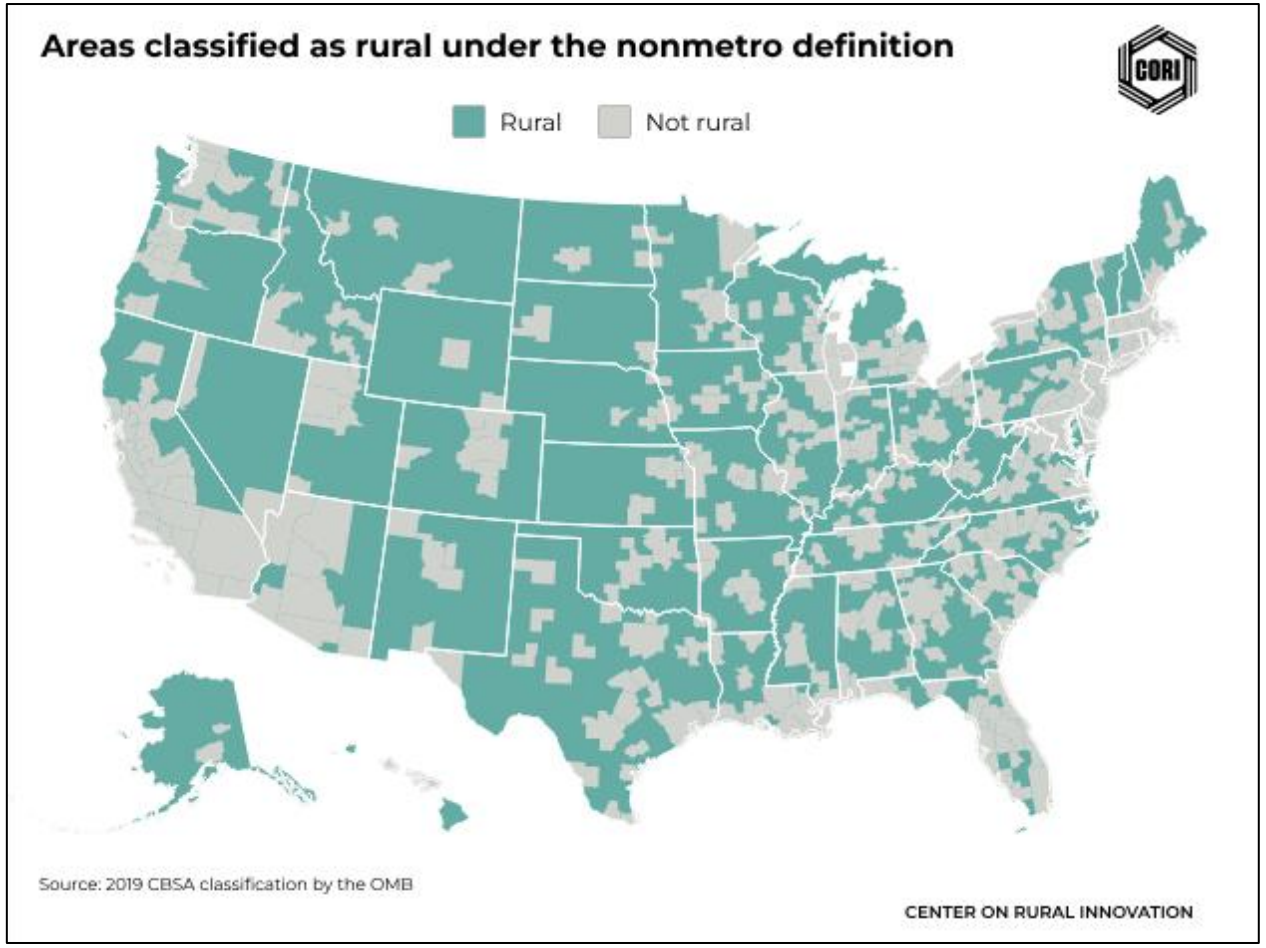
“Perfect Storm” of Factors Creating Rural Palliative Care Inequities

Associations among rurality, persistent poverty, poor health outcomes

Social injustice, racism, experimentation, broken treaties, ‘hit & run’, ‘one-size-fits-all’ causing Medical Mistrust

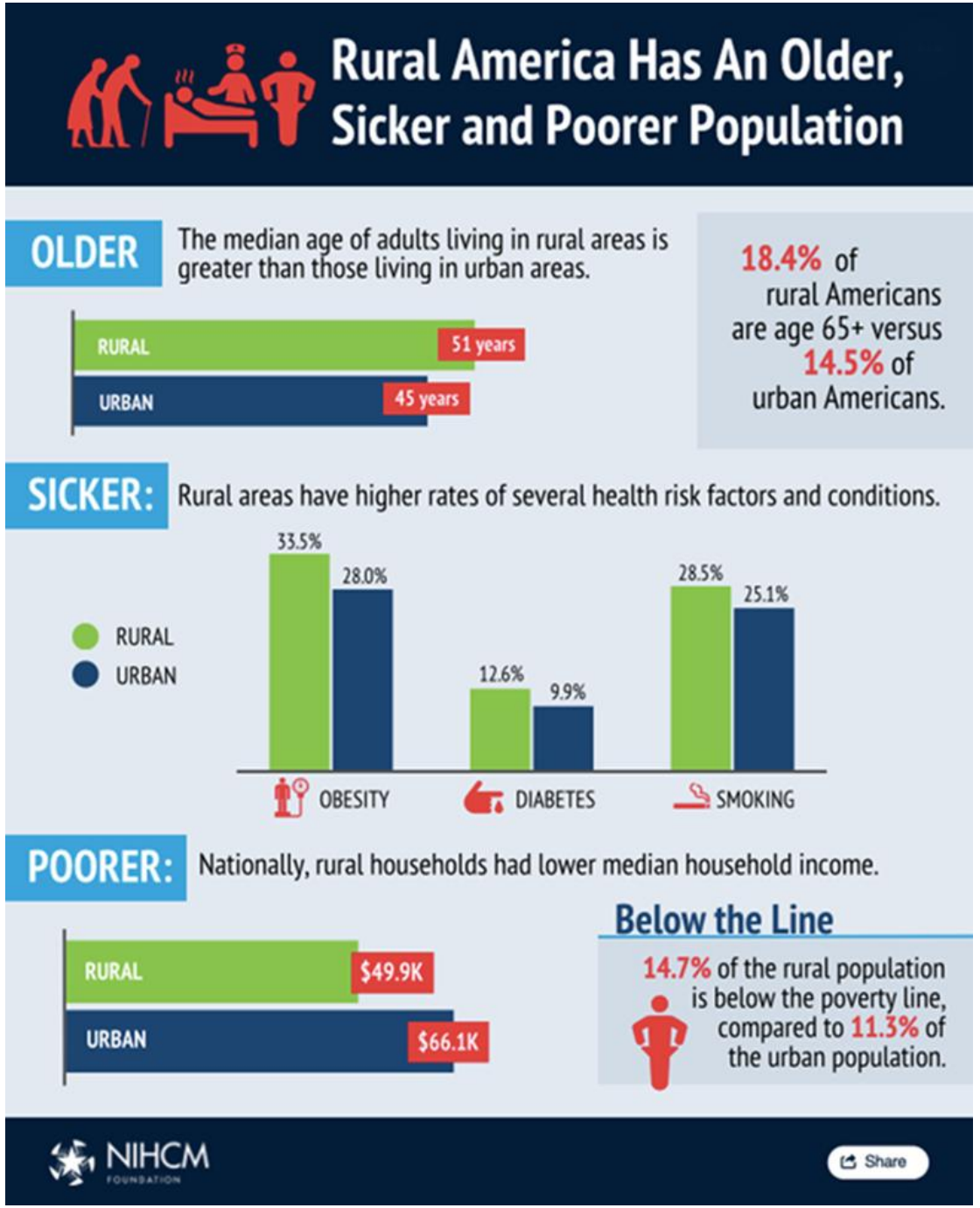
Limited health care, palliative care workforce, & PC-friendly health systems

Bakitas et al., 2015, Cancer Control; Bakitas et al., 2020, J Clin Onc; Marshall et al., 2023, Palliative Medicine



>14% (46m) of the U. S. population lives in rural areas

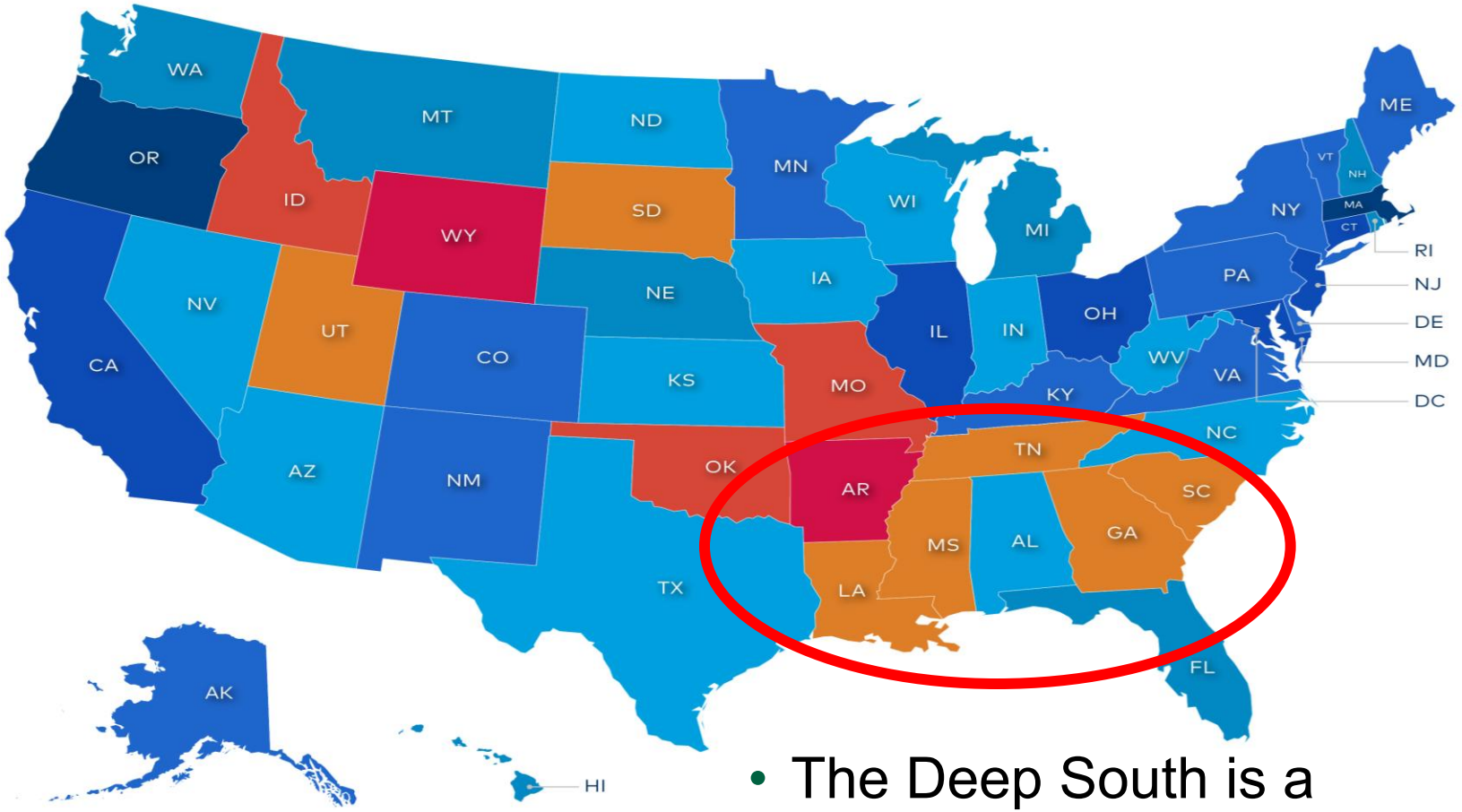
46.7% (28m) are in the South



Rural Areas Lack of Palliative Care Resources

America's Readiness to Meet the Needs of People with Serious Illness

2024 SERIOUS ILLNESS SCORECARD:
A STATE-BY-STATE LOOK AT PALLIATIVE CARE CAPACITY



- The Deep South is a **"palliative care desert"**

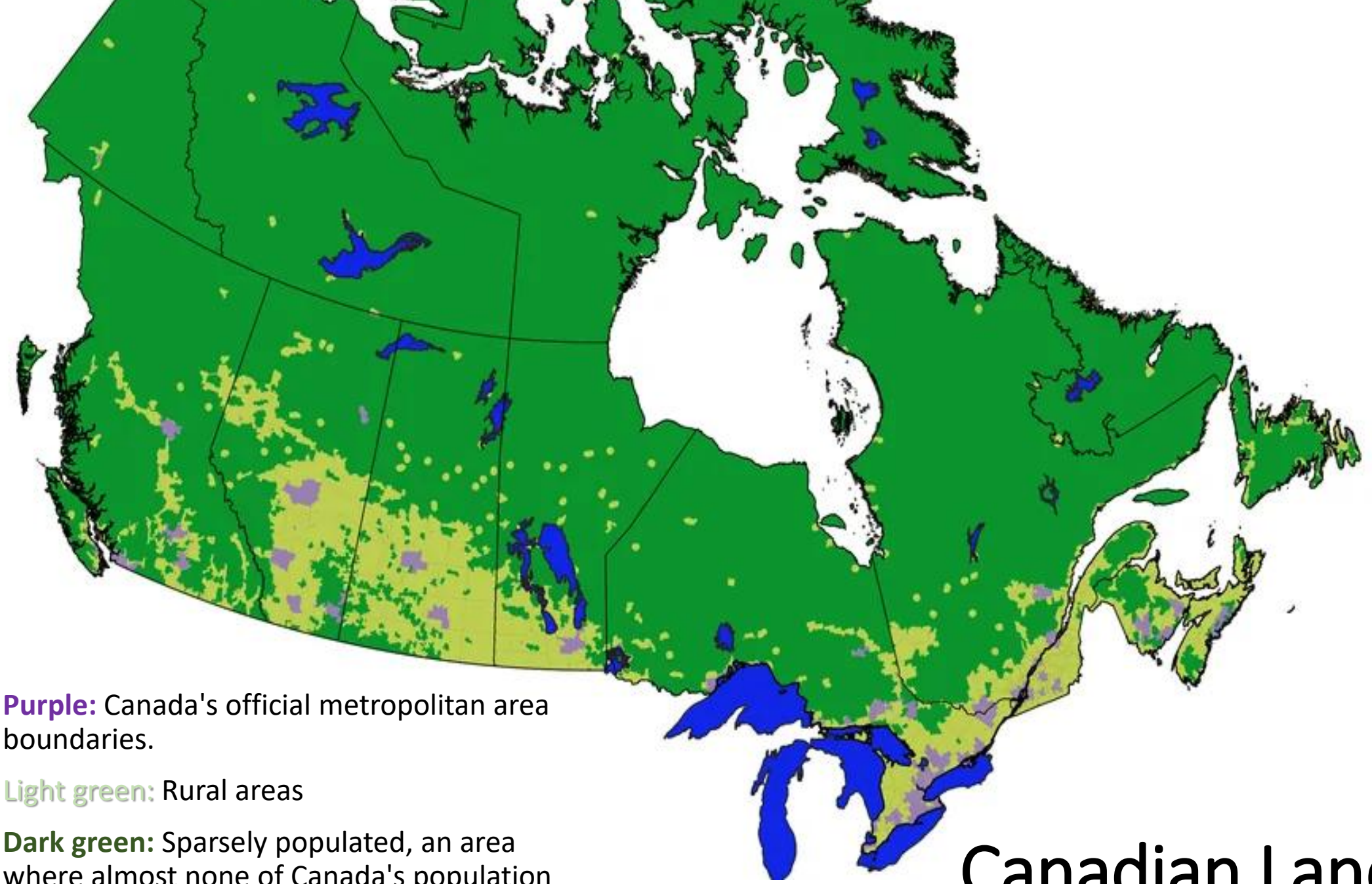
Scorecard Ratings by State 2024

CAPC Serious Illness Scorecard | scorecard.capc.org

State rating by color:

1.0	1.5	2.0	2.5	3.0	3.5	4.0	4.5

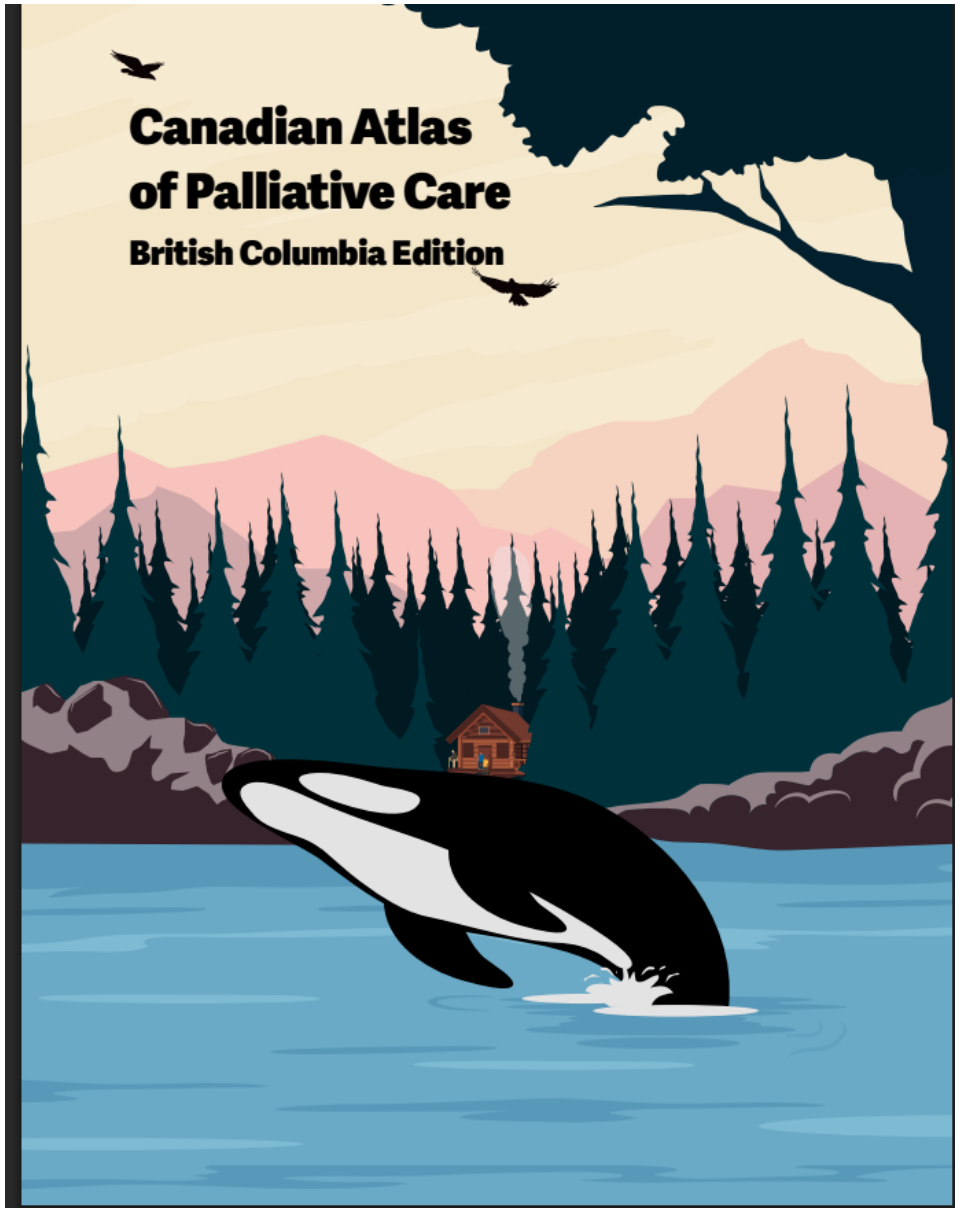
Presented by: Marie A. Ba



- **Purple:** Canada's official metropolitan area boundaries.
- Light green: Rural areas
- **Dark green:** Sparsely populated, an area where almost none of Canada's population lives.

Canadian Landscape

Limited PC Access in Rural Canada



RESULTS: BRITISH COLUMBIA

MAPS

Access to Palliative Home Care Services

Legend

- Major Cities
- Full
- Partial High

References: 1) ESRI Light Gray Basemap (arcgis.com); 2) Regional Health Authority Boundaries (BC Map Hub); Major Cities (The Atlas of Canada Base Maps of BC).

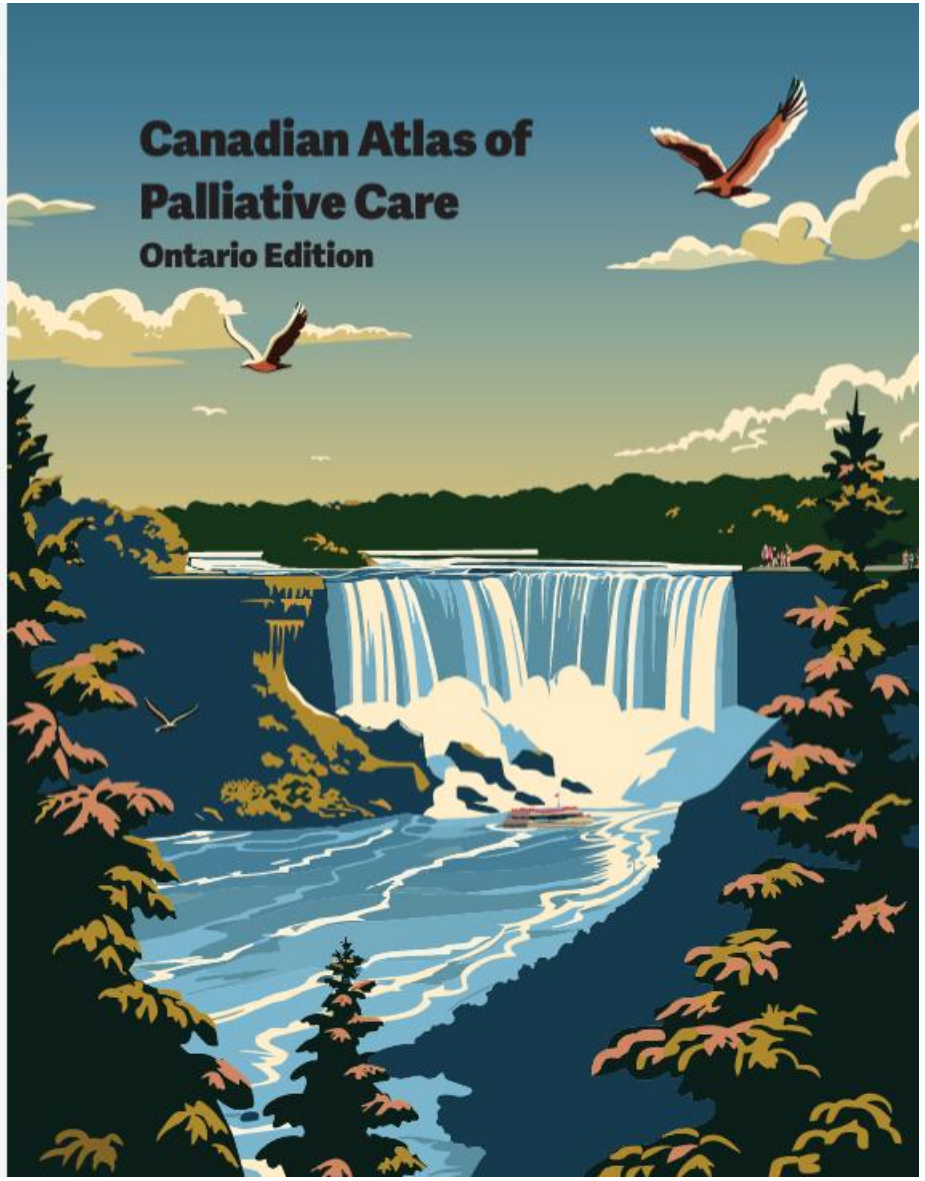
Access to Specialist Level Care Support Teams in Hospital

Legend

- Major Cities
- Full
- Partial High
- Partial Low

References: 1) ESRI Light Gray Basemap (arcgis.com); 2) Regional Health Authority Boundaries (BC Map Hub); Major Cities (The Atlas of Canada Base Maps of BC).

Limited PC Access in Rural Canada



RESULTS: ONTARIO

Access to Specialist Level Care Support Teams in Hospital

Legend
- Major Cities
- Full
- Partial High
- Partial Low
- Minimal/Absent

References: 1) ESRI Light Gray Basemap (arcgis.com); 2) Ontario Health Regions Boundaries (Ministry of Health); Major Cities (Data in Ontario Open Data Working Group).

Access to Palliative Home Care Services

Legend
- Major Cities
- Full
- Partial High
- Partial Low

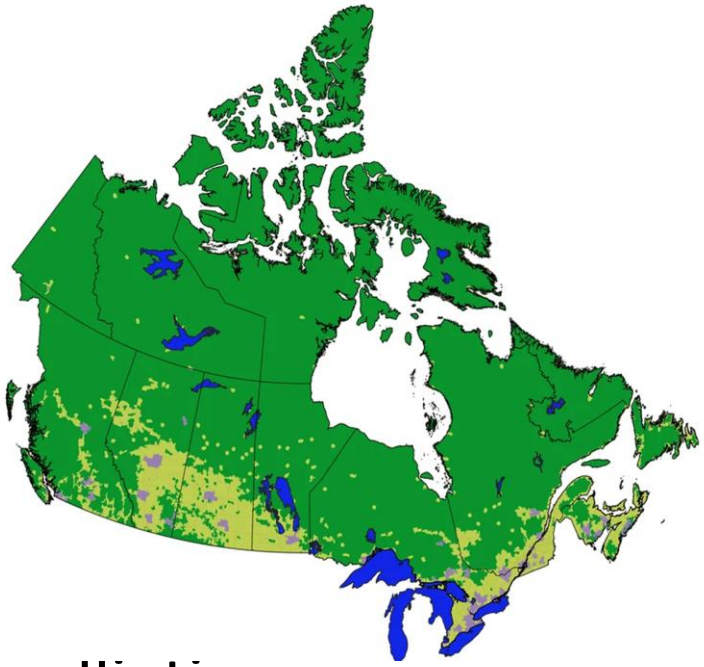
References: 1) ESRI Light Gray Basemap (arcgis.com); 2) Ontario Health Regions Boundaries (Ministry of Health); Major Cities (Data in Ontario Open Data Working Group).

Research Access to health care

Estimated mortality risk and use of palliative care services among home care clients during the last 6 months of life: a retrospective cohort study

Maya Murmann MSc, Douglas G. Manuel MD, Peter Tanuseputro MD, Carol Bennett MSc, Michael Pugliese MSc, Wenshan Li BSc, Rhiannon Roberts MSc, Amy T. Hsu PhD

Cite as: *CMAJ* 2024 February 26;196:E209-21. doi: 10.1503/cmaj.221513



Access to Palliative Care in Canada

- In Canada, a **significant gap** exists in the provision of palliative care services for patients nearing the end of life.
- Only **15% of patients** requiring palliative care receive such services in the year before death.
- Most palliative care visits occur in **the last month of life, primarily in acute care settings.**
- More than **80% of deaths** could benefit from a palliative care approach.

Medical Mistrust Among Rural Populations

Sítima et al. International Journal for Equity in Health (2024) 23:248
https://doi.org/10.1186/s12939-024-02321-1

International Journal for Equity in Health

REVIEW Open Access

Equity of access to palliative care: a scoping review

Gonçalo Sítima[1], Carlos Galhardo-Branco[2] and Paulo Reis-Pina[1,3*]

- Prevalent among **racialized communities, Indigenous populations, & low-income groups**.
- Historical discrimination & systemic racism.
- Misunderstandings about palliative care.
- Lack of culturally sensitive communication and care models

- Felt unprepared for amount of care they needed to provide
- Frustrated with lack of information
- Disrespected by health care team
- Mismatch between expectations & reality

Luymes et al. BMC Palliat Care (2021) 20:149
https://doi.org/10.1186/s12904-021-00843-x

BMC Palliative Care

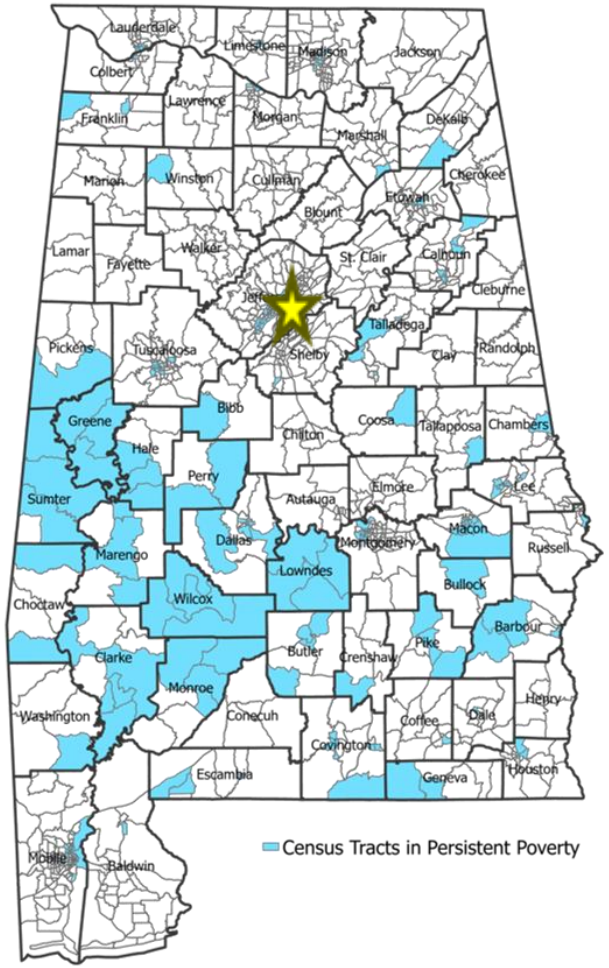
RESEARCH Open Access

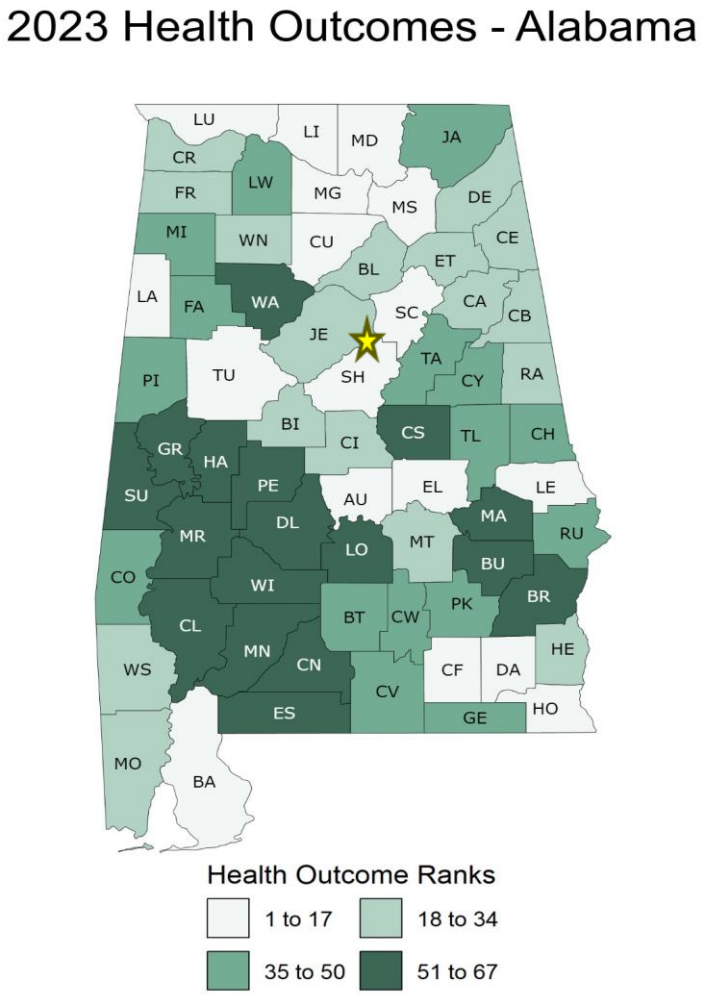
"The system is well intentioned, but complicated and fallible" interviews with caregivers and decision makers about palliative care in Canada

Nicole Luymes[1], Nicole Williams[1*], Liz Garrison[2], Donna Goodridge[3], Maria Silveira[4] and Dawn M. Guthrie[1,5]

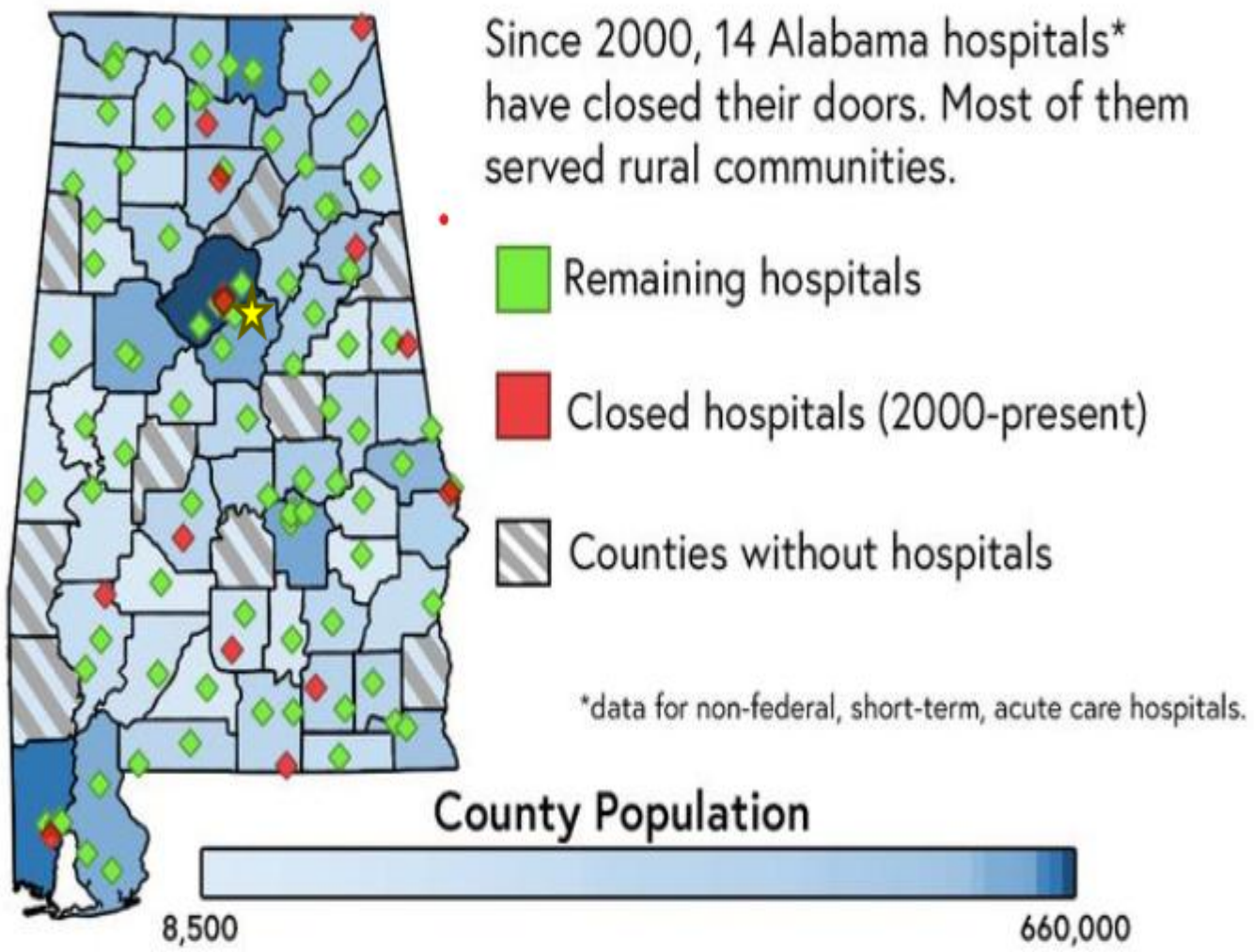
Framework & Plan Address Some Rural Issues

Alabama: Rurality, Persistent Poverty, Poor Health Outcomes





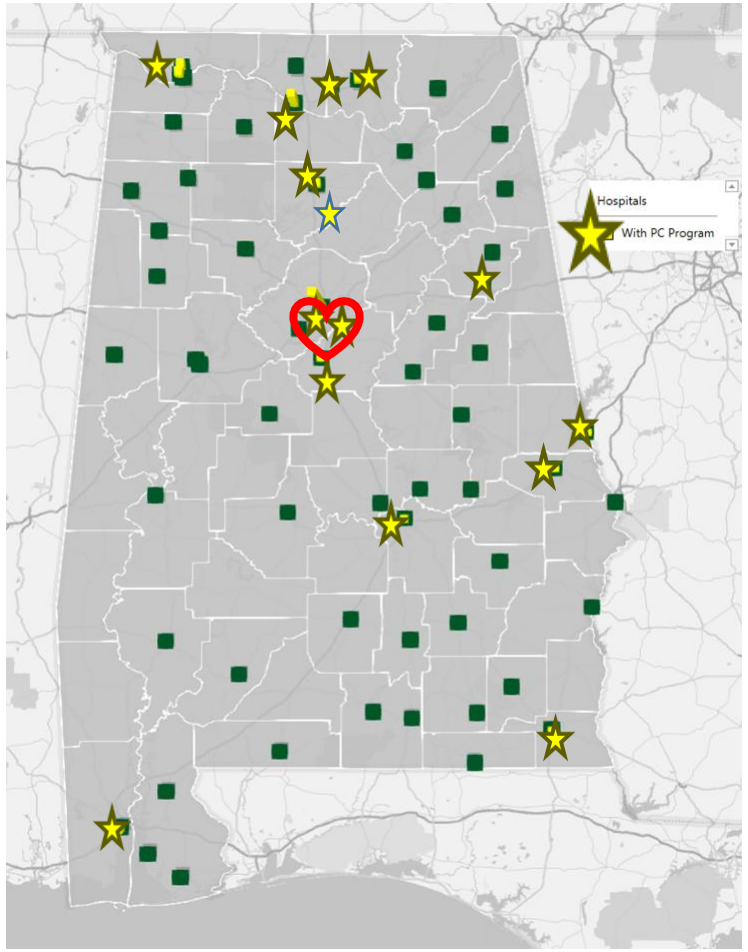
Limited Health Care Access: Rural Hospital Closures Amplify Care Access, Quality, & Inequities



"You probably already know this—but Alabama is one of the states with the most hospitals at risk for closure in the next year. I think there are 28 rural hospitals—60 percent are at risk for closure"

-2023 interview with Rural Hospital CEO
Beasley et al. 2023

Limited Palliative Care Access & Workforce



39.3% (22/56)
of hospitals report palliative services

50% (11/22) public

61.5% (8/13) not-for-profit

4% (3/21) for profit

9
counties have no hospital

14
counties have no hospice services

ALABAMA HOSPITALS

HOSPITALS WITH PALLIATIVE CARE SERVICES

The goal of Palliative Care… improve quality of life for the patient & family. It's provided by a specially-trained team of doctors, nurses, & other specialists who work together with a patient's other doctors to provide an extra layer of support.

Rural Ontario communities hit hard by ER closures, hospitals face staff challenges

By Sharif Hassan • The Canadian Press
Posted November 2, 2022 8:49 am · **5 min read**

How do we provide palliative care in rural areas with no foundational layer of primary health care?
Too poor for palliative care

Objectives

Review rural characteristics that create disparities in palliative care.

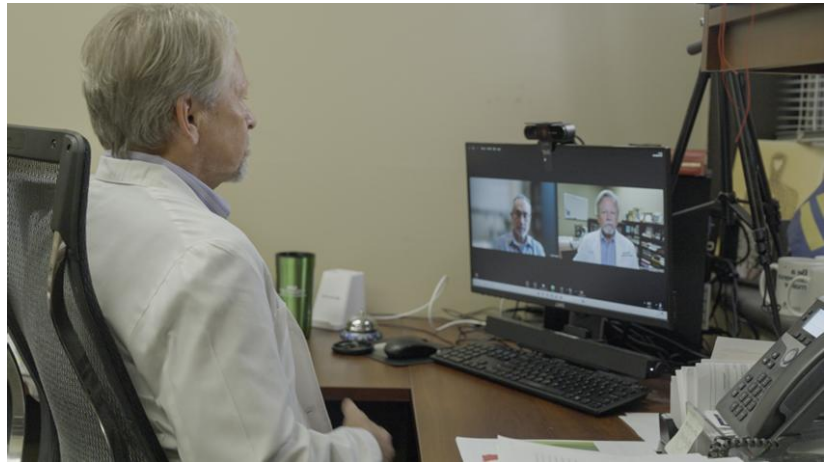
Consider approaches that can enhance access & acceptability

Discuss strategies to implement culturally-based palliative care.

Increasing ACCESS to Reduce Disparities

Implement technology-aided interventions

- Telehealth, ePROs

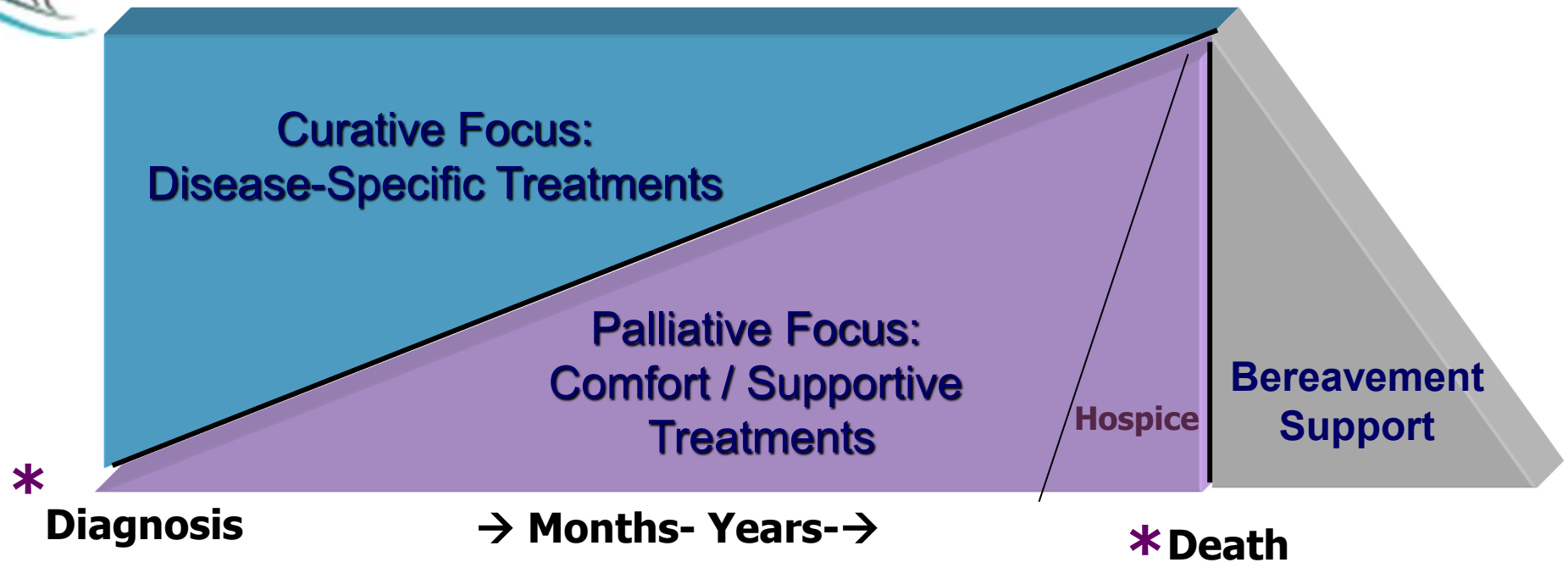


Project ENABLE

PROMOTING EXCELLENCE
IN END-OF-LIFE CARE

A NATIONAL PROGRAM OF
THE ROBERT WOOD JOHNSON FOUNDATION

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



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

*Adapted from World Health Organization 1990

Patient, Family, Clinician Focus Groups

What do you wish you knew when you were first diagnosed that would have helped you to cope better with your illness?

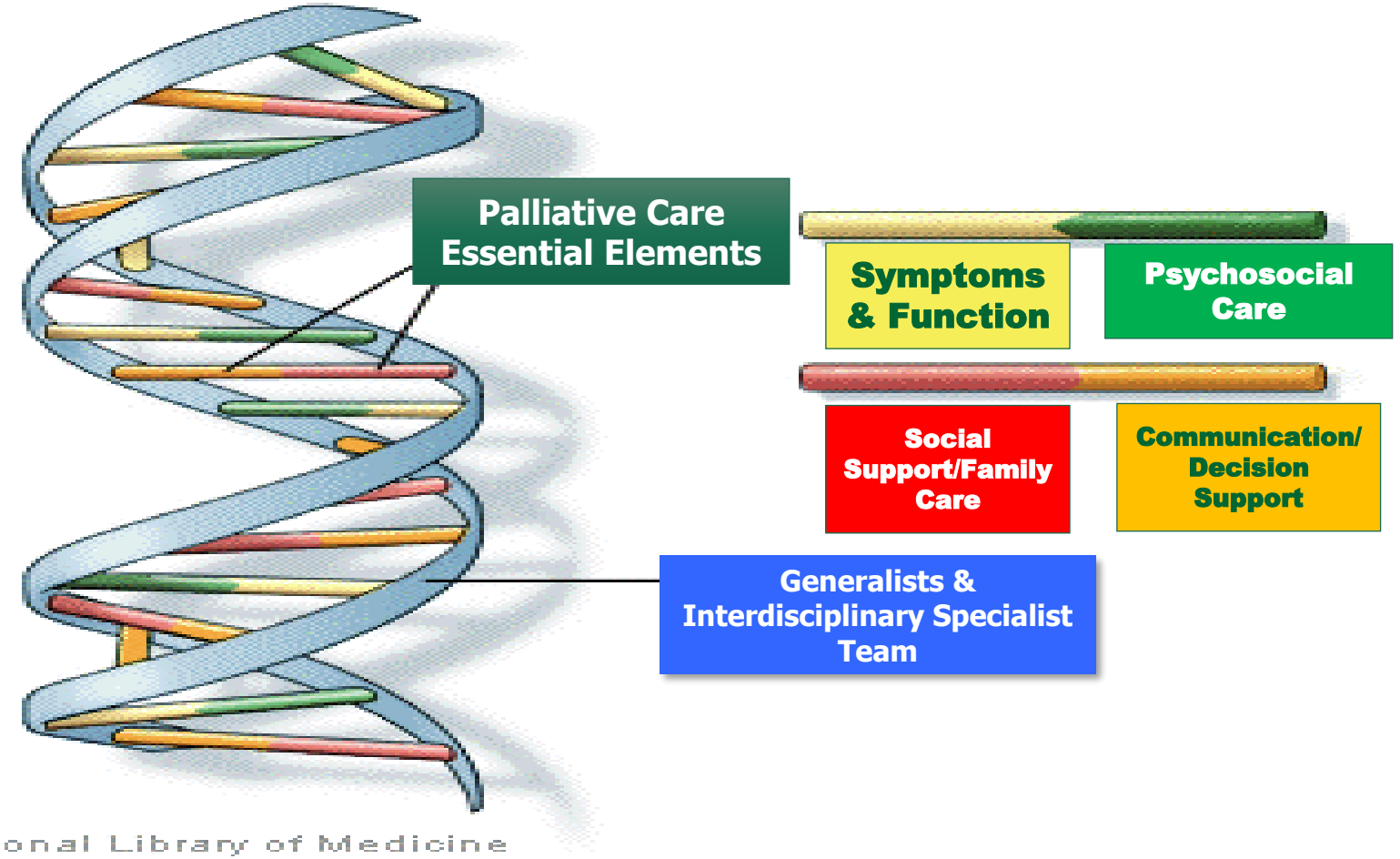
What is ENABLE?

Key Objectives:

- Develop and maintain a therapeutic relationship with patients and their family caregiver(s)
- Improve physical and psychological symptoms through self-care
- Assess and enhance illness understanding and prognostic awareness
- Facilitate treatment/healthcare decision-making
- Plan for the future/advance care planning
- Enhance communication and leverage local community resources and social support
- Facilitate life reflection and legacy formation

Educate
Nurture
Advise
Before
Life
Ends

Defining & Delivering the "DNA" of Palliative Care



ENABLE I-Lessons Learned

- **Early (outpatient) Palliative Care is feasible**
  - N=380 participants; 268 died; 130 proxies

- **Compared to Local and National Benchmarks**
  - ⬆ clinician/patient goals of care communication
  - ⬆ advanced directives, home death, hospice use & ALOS
  - ⬇ hospital and nursing home deaths

*To improve accessibility, need hybrid delivery: in-person (IRL) & telephone (URL) components

Cancer. 112(8):1854-1861; PMID: 18306393; PMCID: 3638939

What ENABLE patients get…

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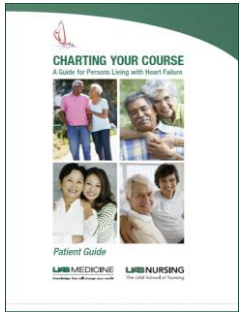

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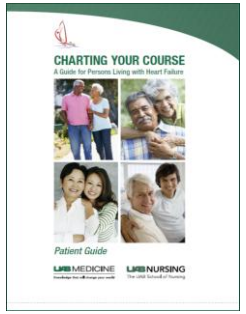

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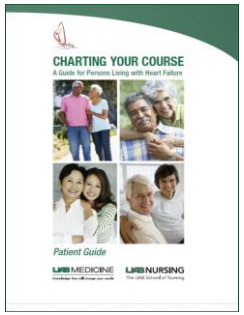

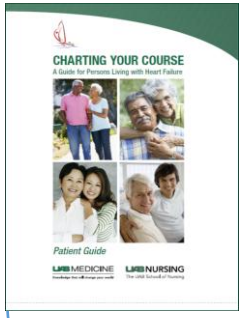

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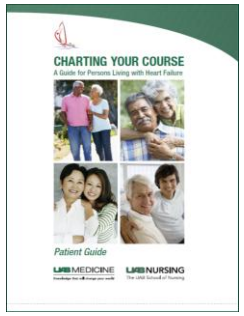

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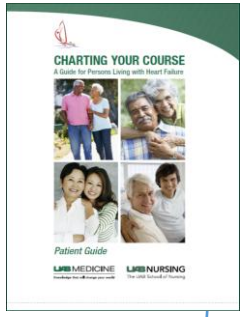

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Comprehensive palliative care assessment

Konda Keebler, MSN, RN
Nurse Coach

Elizabeth Sockwell, BSN, RN
Nurse Coach

Rachel Wells, MSN, RN
Nurse Coach

Crystal Nwagwu, MSN, RN
Nurse Coach

Monthly check-in calls up to 48 weeks

Charting Your Course

***6* Sessions (30-60 min)**

ENABLE telehealth early PC improves patient & caregiver-reported outcomes

Pts had improved QOL, mood, & trends towards improved symptoms & survival

ORIGINAL CONTRIBUTION

JAMA

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

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

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

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

Interventions A multicomponent, psychoeducational intervention (Project ENABLE [Educate, Nurture, Advise, Before Life Ends]) conducted by advanced practice nurses consisting of 4 weekly educational sessions and monthly follow-up sessions until death or study completion (n=161) vs usual care (n=161).

Main Outcome Measures Quality of life was measured by the Functional Assessment of Chronic Illness Therapy for Palliative Care (score range, 0-184). Symptom intensity was measured by the Edmonton Symptom Assessment Scale (score range, 0-900)

IFTY PERCENT OF PERSONS WITH

No difference in PROs;
Early pts had ↑1 yr. survival

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, Dartmouth College, Hanover, NH; and

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

Caregivers had:
↓depressed mood
↓ stress burden
(*trend*) ↑ QOL

JOURNAL OF CLINICAL ONCOLOGY | ORIGINAL REPORT

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

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

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

Outpatient PC via Telehealth is not inferior to in-person…

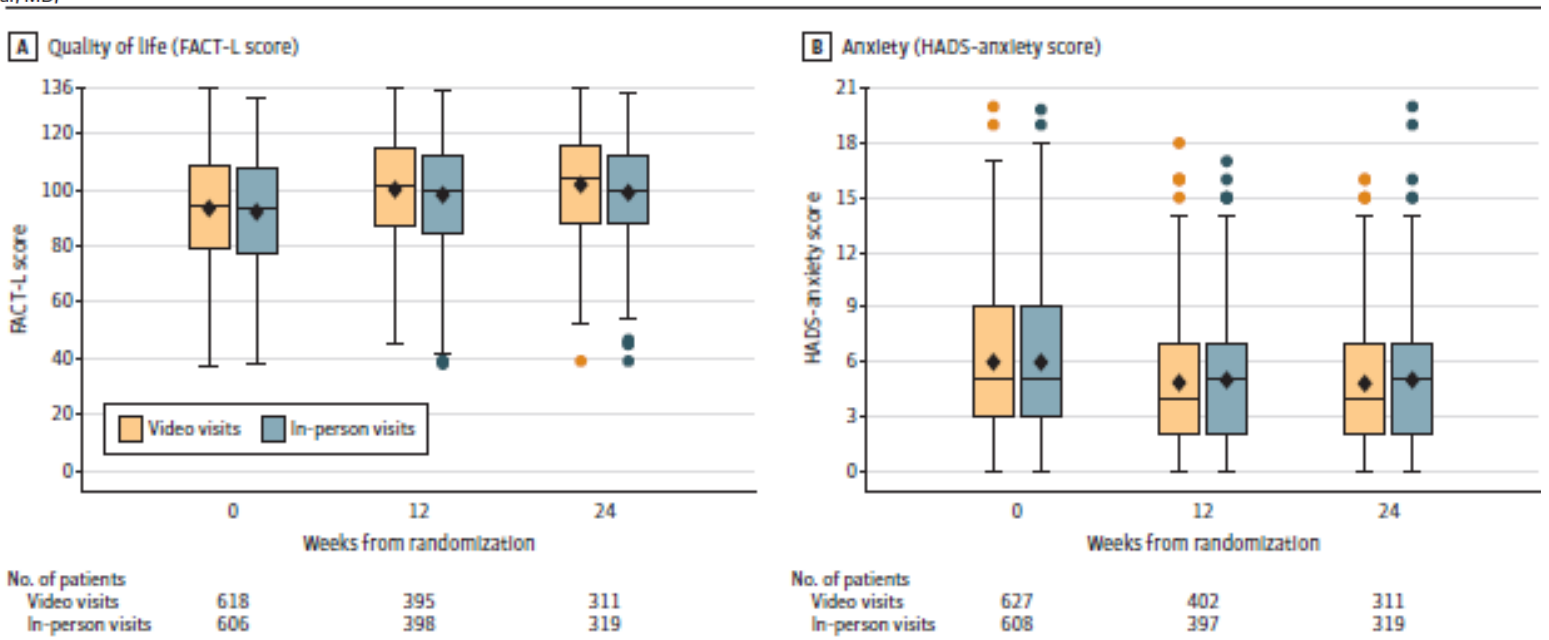
Research

JAMA | Original Investigation

Telehealth vs In-Person Early Palliative Care for Patients With Advanced Lung Cancer

A Multisite Randomized Clinical Trial

Joseph A. Greer, PhD; Jennifer S. Temel, MD; Areej El-Jawahri, MD; Simone Rinaldi, ANP-BC; Mihir Kamdar, MD; Elyse R. Park, PhD, MPH; Nora K. Horick, MS; Kedie Pintro, MS; Dustin J. Rabideau, PhD; Lee Schwamm Josephine Feliciano, MD; Isaac Chua, MD, MPH; Konstantinos Leventakos, MD, PhD; Stacy M. Fischer, Toby C. Campbell, MD; Michael W. Rabow, MD; Finly Zachariah, MD; Laura C. Hanson, MD; Sara F. Mart Maria Silveira, MD; Laura Shoemaker, DO; Marie Bakitas, DNSc; Jessica Bauman, MD; Lori Spoozak, MD Carl Grey, MD; Leslie Blackhall, MD; Kimberly Curseen, MD; Sean O'Mahony, MB, BCh, BAO; Melanie M Ramona Rhodes, MD; Amelia Cullinan, MD; Vicki Jackson, MD; for the REACH PC Investigators



Increasing ACCESS to Reduce Disparities

Implement technology-aided interventions

- Telehealth, ePROs

Diversify workforce

- Primary palliative education
- Lay navigators, community workforce
- Leveraging interdisciplinary team

PRIMARY PALLIATIVE CARE INCREASES ACCESS VIA ↑PC WORKFORCE

TABLE 1. Primary Palliative Care Versus Specialty Palliative Care

Primary Palliative Care Provided by Oncology Clinicians	Specialty Palliative Care
Assessment and management of symptoms and physical needs	Extra layer of support for patients with advanced disease and those at end of life
Assessment and management of psychosocial and spiritual concerns	Consultation for management of complex physical, psychosocial, or spiritual concerns
Attention to cultural aspects of care including ethical issues	Communication with patients and families about goals of care and end of life care decisions
Coordination of supportive care services and referrals to specialty palliative care or hospice	

ASCO Special Articles

Check for u

Palliative Care for Patients With Cancer: ASCO Guideline Update

Justin J. Sanders, MD, MSc[1]; Sarah Temin, MSPH[2]; Arun Ghoshal, MBBS, MD, MRes[3]; Erin R. Alesi, MD[4]; Zipporah Vunoro Ali, MD[5]; Cynthia Chauhan, MSW[6]; James F. Cleary, MD[7]; Andrew S. Epstein, MD[8]; Janice I. Firn, PhD, MSW, HEC-C[9]; Joshua A. Jones, MD, MA[10]; Mark R. Litzow, MD[11]; Debra Lundquist, PhD, RN[12]; Mabel Alejandra Mardones, MD[13]; Ryan David Nipp, MD, MPH[14]; Michael W. Rabow, MD[15]; William E. Rosa, PhD, MBE, APRN[8]; Camilla Zimmermann, MD, PhD, FRCPC[3]; and Betty R. Ferrell, PhD[16]

DOI https://doi.org/10.1200/JCO.24.00542

What Happens When "Culture" is Not Taken into Account?
CANCER COOPERATIVE GROUP CLINICAL TRIAL CULTURE

ORIGINAL CONTRIBUTION

NATIONAL CANCER INSTITUTE JAMA

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

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

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

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

Interventions A multicomponent, psychoeducational intervention (Project ENABLE [Educate, Nurture, Advise, Before Life Ends]) conducted by advanced practice nurses consisting of 4 weekly educational sessions and monthly follow-up sessions until death or study completion (n = 161) vs usual care (n = 161).

Main Outcome Measures Quality of life was measured by the Functional Assess-

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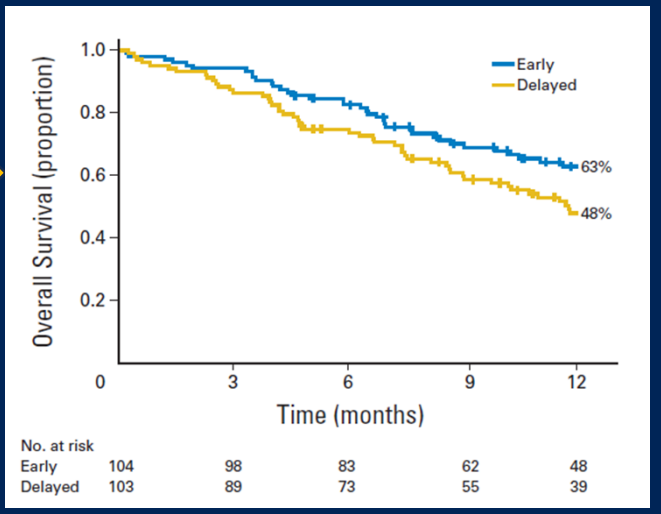
Published online ahead of print at www.jco.org on March 23, 2015.

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

A B S T R A C T

Purpose

Randomized controlled trials have supported integrated oncology and palliative care (PC);



Zubkoff et al. Implementation Science (2021) 16:25
https://doi.org/10.1186/s13012-021-01086-3

Implementation Science

STUDY PROTOCOL Open Access

A cluster randomized controlled trial comparing Virtual Learning Collaborative and Technical Assistance strategies to implement an early palliative care program for patients with advanced cancer and their caregivers: a study protocol

Lisa Zubkoff[1,2*], Kathleen Doyle Lyons[3,4], J. Nicholas Dionne-Odom[5,6,7], Gregory Hagley[3], Maria Pisu[1,7], Andres Azuero[1,5,6], Marie Flannery[8], Richard Taylor[5,6], Elizabeth Carpenter-Song[9], Supriya Mohile[8†] and Marie Anne Bakitas[5,6,7†]

The ENABLE IV Implementation Trial (2018-2024)
(NCI 1 R01CA229197-01 PI: Zubkoff; Co-Is: Bakitas, Odom)

What Happens When "Culture" is Not Taken into Account?
CANCER COOPERATIVE GROUP CLINICAL TRIAL CULTURE

The NEW ENGLAND JOURNAL of MEDICINE

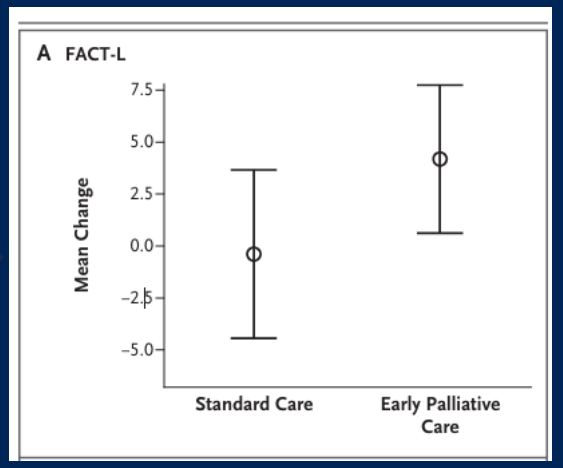
CURRENT ISSUE SPECIALTIES TOPICS

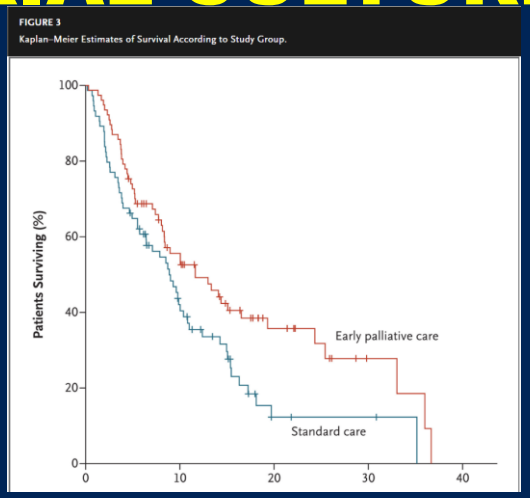
ORIGINAL ARTICLE

Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer

Authors: Jennifer S. Temel, M.D., Joseph A. Greer, Ph.D., Alona Muzikansky, M.A., Emily R. Gallagher, R.N., Sonal Admane, M.B., B.S., M.P.H., Vicki A. Jackson, M.D., M.P.H., Constance M. Dahlin, A.P.N., Craig D. Blinderman, M.D., Juliet Jacobsen, M.D., William F. Pirl, M.D., M.P.H., J. Andrew Billings, M.D., and Thomas J. Lynch, M.D. Author Info & Affiliations

Published August 19, 2010 | N Engl J Med 2010;363:733-742 | DOI: 10.1056/NEJMoa1000678 | VOL. 363 NO. 8





NEJM Evidence

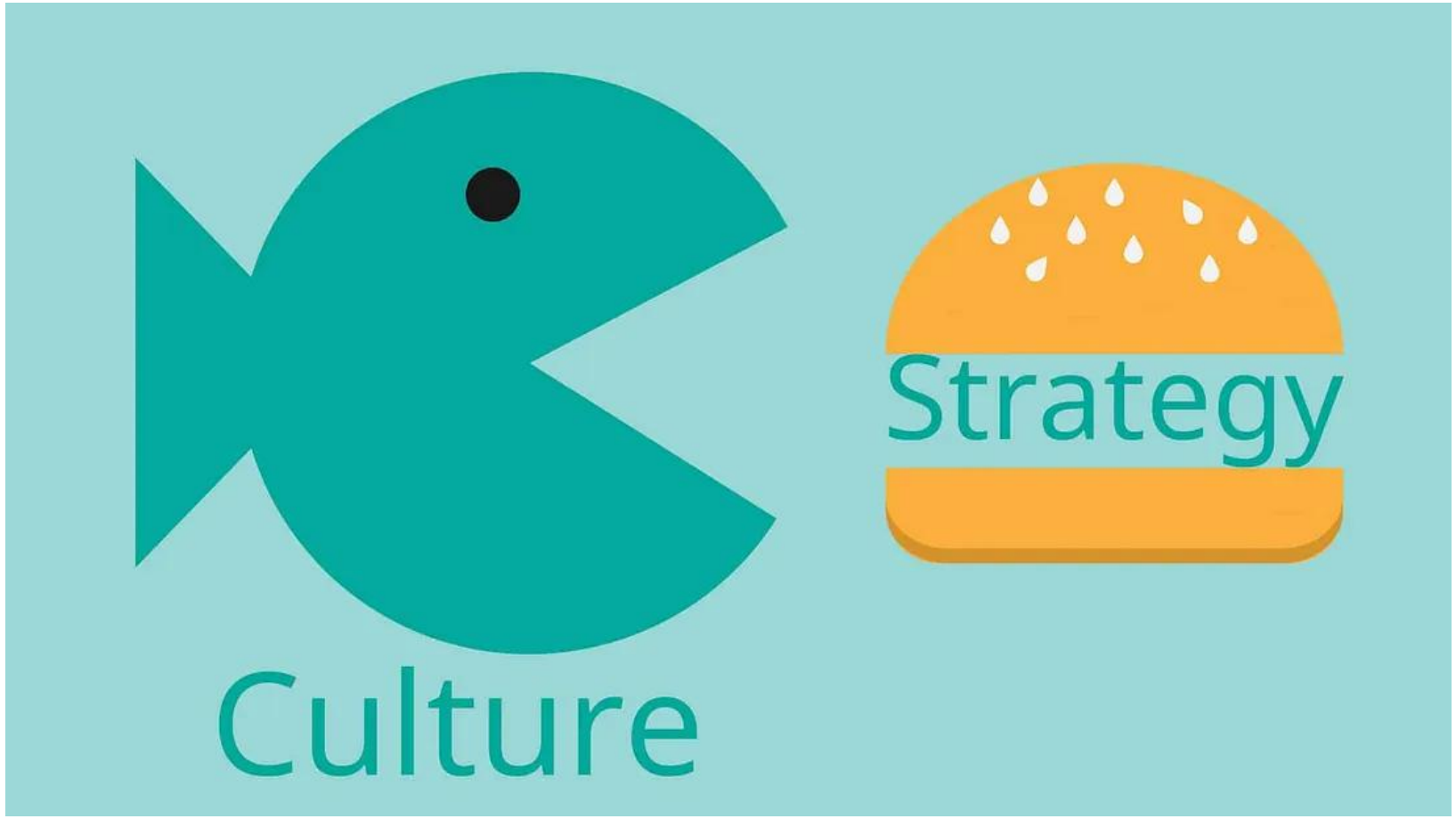
Published June 28, 2022
NEJM Evid 2022; 1 (7)
DOI: 10.1056/EVIDctcs2200122

CLINICAL TRIALS CASE STUDY

Pitfalls and Prospects — Lessons Learned from Early Palliative Care Research

Joseph A. Greer, Ph.D.,[1,2] and Jennifer S. Temel, M.D.[1,2]

Culture eats strategies for lunch…



Objectives

Review rural characteristics that create disparities in palliative care access & acceptability

Consider community-informed approaches that can enhance access & acceptability

Discuss strategies to implement culturally-based palliative care models.

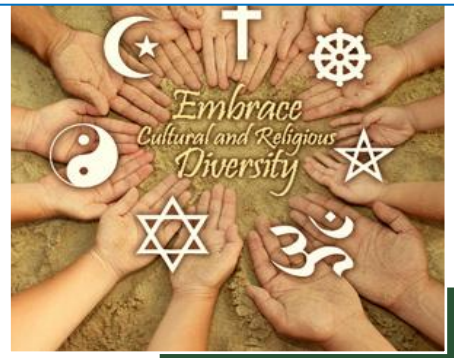
Beyond Broadband—All aBout Culture

SPECIAL SERIES: PALLIATIVE CARE: SCIENCE AND PRACTICE

Forging a New Frontier: Providing Palliative Care to People With Cancer in Rural and Remote Areas

Marie Bakitas, DNSc, CRNP[1]; Kristen Allen Watts, PhD[1]; Emily Malone, MPH[1]; J. Nicholas Dionne-Odom, PhD, RN[1]; Susan McCammon, MD[1]; Richard Taylor, DNP, CRNP[1]; Rodney Tucker, MD[1]; and Ronit Elk, PhD[1]

- **Context:** Culture Clash between palliative care & local culture
- **Strategy:** Develop community partnerships



- **Context:** Inattention to religion/spirituality
- **Strategy:** Partner with local spiritual leaders for guidance on how to leverage religion & spirituality to make palliative care culturally-responsive.

- **Context:** Local "healers" have a powerful influence on advanced illness
- **Strategy:** Partner with healers to promote local palliative care resources rather than transferring patients to distant centers.

Promoting Palliative Care in Rural Communities: Community-Engaged Strategies & Solutions

- **Technology-Enabled Solutions**
  - Telehealth
  - eHealth-Mobile health
  - Video-consultations
  - Remote Monitoring
- **Community-Academic Partnerships**
  - Home visits
  - Community (Lay) Health Workers for Patients & Families
  - Primary palliative care skills (ELNEC)
  - PC Networks & Advisory Groups

House call: Susan McCammon (right), a surgeon and palliative medicine physician at the University of Alabama at Birmingham, regularly visits patients such as Janice Bass, shown wi her dog, Abbey, to manage treatment and support advance care planning.

DOI: 10.1377/hlthaff.2019.01470

Bringing Palliative Care To Underserved Rural Communities

With home visits and modern technology, palliative medicine physician in Alabama are overcoming long-held resistance.

BY CHARLOTTE HUFF

How to bring specialty palliative to small rural hospitals for seriously ill patients?

Culturally-informed Accessible Care: Doing it Right

JAMA Network | Open

Original Investigation | Critical Care Medicine

Palliative Video Consultation and Symptom Distress Among Rural Inpatients
A Randomized Clinical Trial

Marie A. Bakitas, DNSc, RN; Shena Gazaway, PhD, RN; Felicia Underwood, MSW, MPS, LICSW-S; Christiana Ekelem, BS; Vantrice T. Heard, PhD; Richard Kennedy, MD, PhD; Andres Azuero, PhD; Rodney Tucker, MD, MMM; Susan McCammon, MD, PhD; Joshua M. Hauser, MD; Lucas McElwain, MD; Ronit Elk, PhD

1 R01 NR017181-01 Elk & Bakitas (MPI) & a Diversity Supplement (Gazaway-R01NR017181-03S);
ClinicalTrials.gov Identifier: NCT03767517

NIH National Institute of Nursing Research

COMMUNITY Tele-Pal

PRESENTED BY:
Marie Anne Bakitas, DNSc, NP-C, AOCN, FPCN

Tailoring Palliative Care to Rural South Black & White Communities Videoconsultation in 3 Rural Hospitals

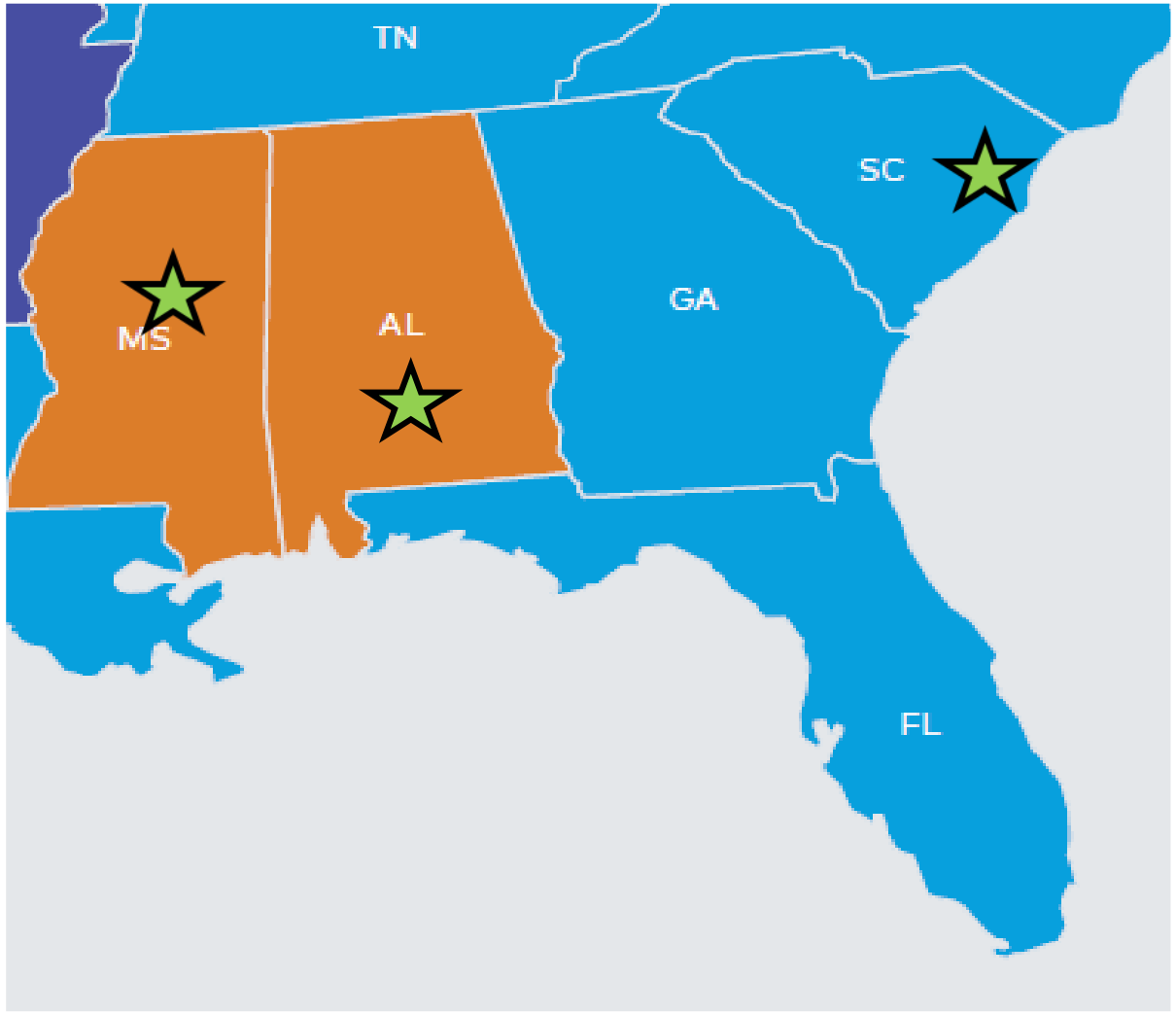
Watts *et al. Trials* (2020) 21:672
https://doi.org/10.1186/s13063-020-04567-w

Trials

STUDY PROTOCOL Open Access

Community Tele-pal: A community-developed, culturally based palliative care tele-consult randomized controlled trial for African American and White Rural southern elders with a life-limiting illness

Kristen Allen Watts[1], Shena Gazaway[2], Emily Malone[1], Ronit Elk[1,3], Rodney Tucker[1,3], Susan McCammon[3,4], Michele Goldhagen[5], Jacob Graham[6], Veronica Tassin[7], Joshua Hauser[8], Sidney Rhoades[9], Marjorie Kagawa-Singer[10], Eric Wallace[11], James McElligott[12], Richard Kennedy[1] and Marie Bakitas[13*]



COMMUNITY TELE-PAL: STUDY SITES

Aiken Regional MEDICAL CENTERS

Aiken, SC [245 beds]

ANDERSON Regional Health System

Meridian, MS [400 beds]

Russell Medical

Alexander-City, AL [80 beds]

Presented by: Marie A. Bakitas DNSc, RN, NP-C, AOCN, FPCN, FAAN

Co-creating a Culturally-Based Palliative Care Consultation Protocol

1. Gathered Community Voices

Elk R21 (2013-

"…death and dying has a lot to do with our faith. If we believe whatever the Word say… it has to do with our faith and our culture and our community at large. Remember, we went to the church for everything. Church was the leader of everything"

Tailoring Palliative Care to Rural South Black & White Communities

Health Equity
Volume 4.1, 2020
DOI: 10.1089/heq.2019.0120

Health Equity

Mary Ann Liebert, Inc. publishers

ORIGINAL ARTICLE Open Access

Developing and Testing the Feasibility of a Culturally Based Tele-Palliative Care Consult Based on the Cultural Values and Preferences of Southern, Rural African American and White Community Members: A Program by and for the Community

Ronit Elk,[1,*] Linda Emanuel,[2] Joshua Hauser,[2] Marie Bakitas,[1,3] and Sue Levkoff[4]

Phase I: Themes - AA Focus Groups

- We take care of our own.
- Family takes care of our loved ones in our own home.
- Hospice equals death.

Phase II: Programmatic Implications for AA Patients & Families

- Do not raise topic of hospice.
- If family discusses need for assistance/feeling overburdened. Explain about **help at home**.
- Stress-hospice staff not there to take over, only assist as needed.

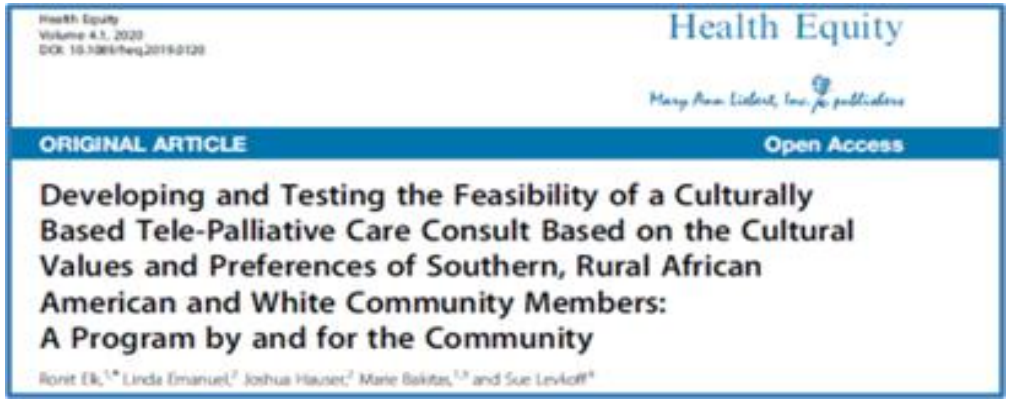
Co-creating a Culturally-Based Palliative Care Consultation Protocol

1. Gathered Community Voices

Elk R21 (2013-2016)

2. Trained Physicians in Consult

(7/2018-9/2019)



Health Equity

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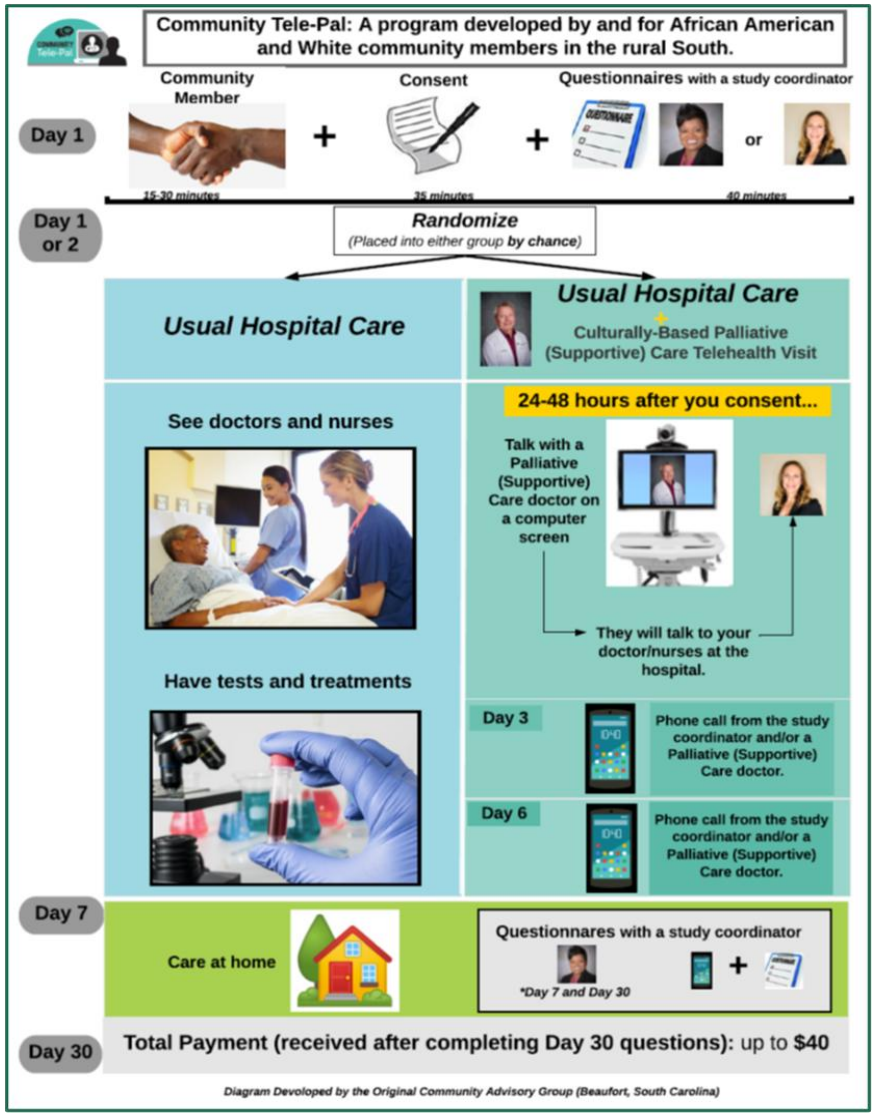
Co-creating a Culturally-Based Palliative Care Consultation Protocol

3. Local CAGs Informed Procedures



4. CAG Members Aid Recruitment

Review > J Pain Symptom Manage. 2023 Mar 3;S0885-3924(23)00398-6.
doi: 10.1016/j.jpainsymman.2023.02.319. Online ahead of print.

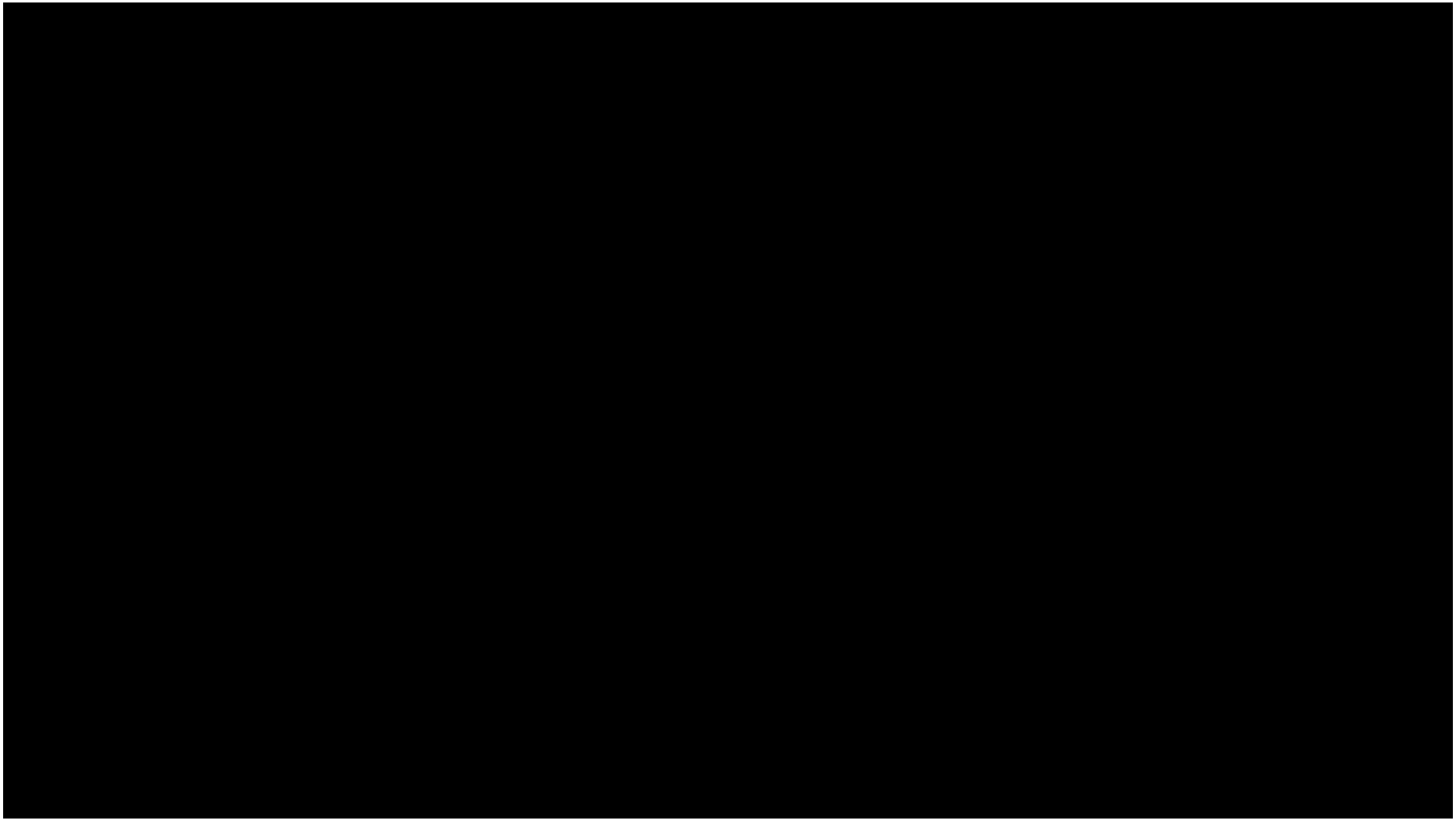
Community informed recruitment: a promising method to enhance clinical trial participation

Shena Gazaway [1], Marie Bakitas [2], Felicia Underwood [3], Christiana Ekelem [3], Marlee Duffie [4], Sheila McCormick [5], Vantrice Heard [4], Audrey Colvin [6], Ronit Elk [3]

Affiliations + expand

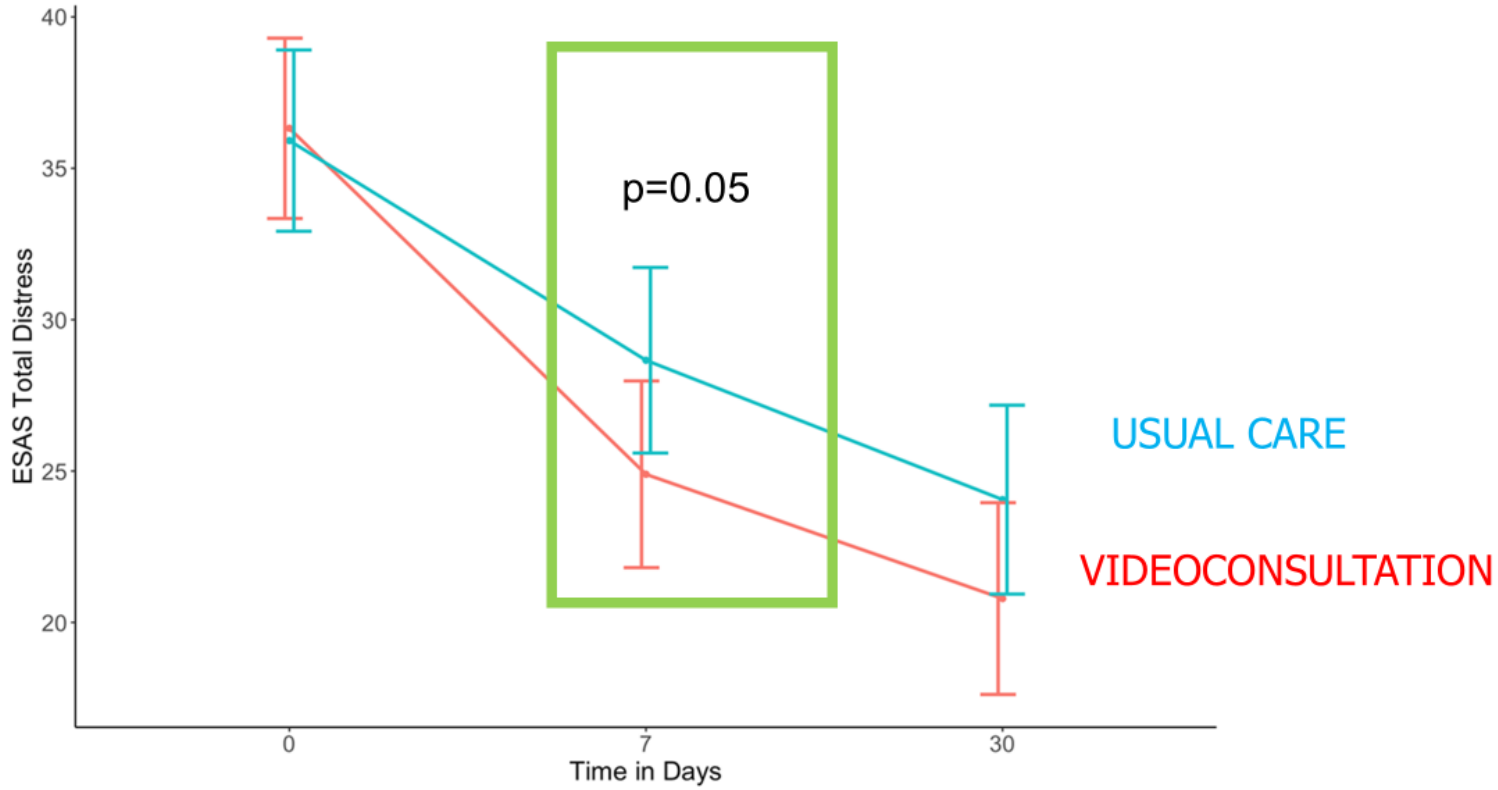
PMID: 36871774 DOI: 10.1016/j.jpainsymman.2023.02.319

Presented by: Marie A. Bakitas DNSc, RN, NP-C, AOCN, FPCN, FAAN



Culturally-Informed Care Gets Results

Results: ESAS Symptom Distress Day 7



JAMA Network | Open

Original Investigation | Critical Care Medicine

Palliative Video Consultation and Symptom Distress Among Rural Inpatients
A Randomized Clinical Trial

Marie A. Bakitas, DNSc, RN; Shena Gazaway, PhD, RN; Felicia Underwood, MSW, MPS, LICSW-S; Christiana Ekelem, BS; Vantrice T. Heard, PhD; Richard Kennedy, MD, PhD; Andres Azuero, PhD; Rodney Tucker, MD, MMM; Susan McCammon, MD, PhD; Joshua M. Hauser, MD; Lucas McElwain, MD; Ronit Elk, PhD

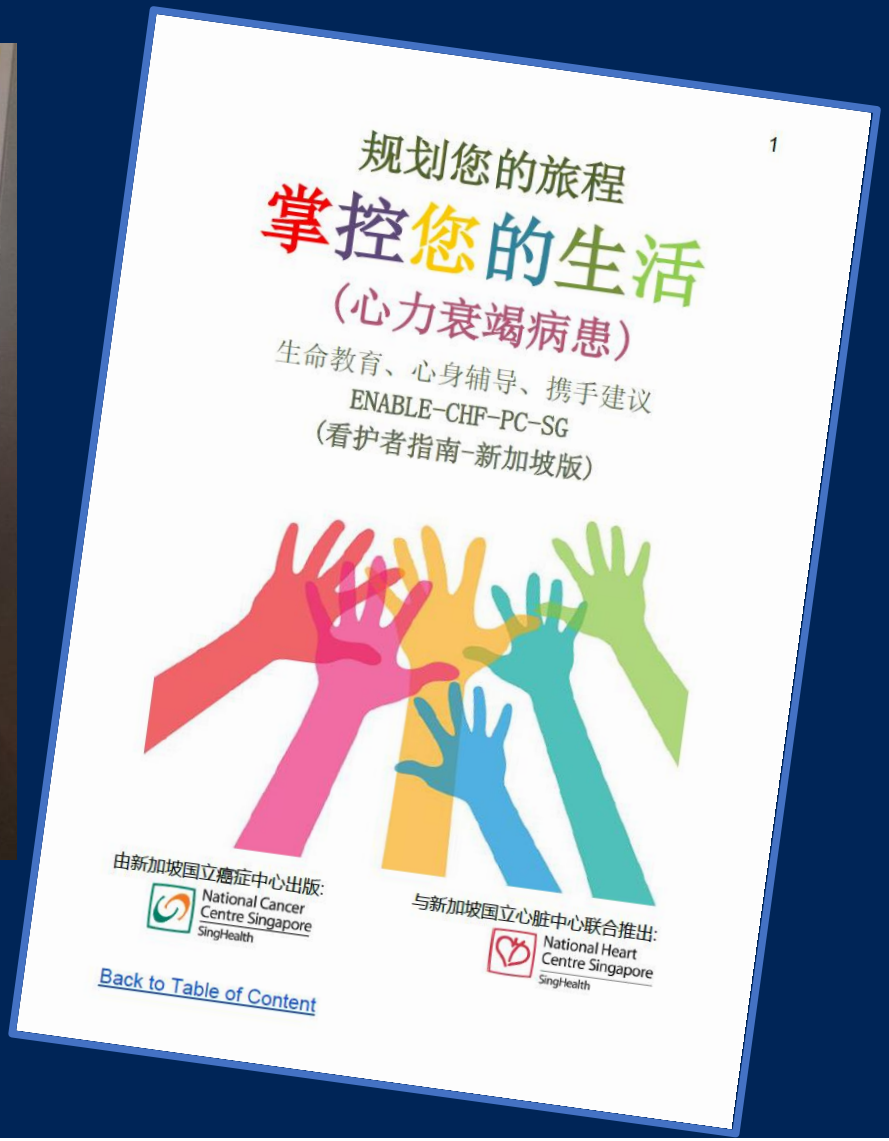
ENABLE - Persian Adaptation


Contemporary Clinical Trials Communications 33 (2023) 101114
Contents lists available at ScienceDirect
Contemporary Clinical Trials Communications
journal homepage: www.elsevier.com/locate/conctc
ELSEVIER

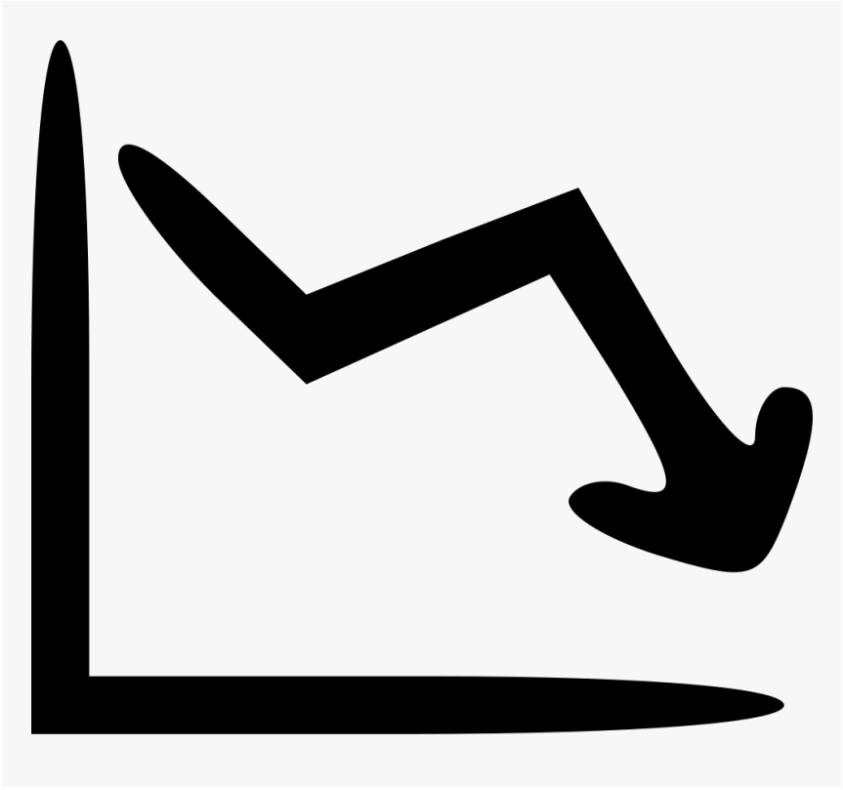
The feasibility and acceptability of an early tele-palliative care intervention to improve quality of life in heart failure patients in Iran: A protocol for a randomized controlled trial

Arvin Mirshahi [a,b], Shahrzad Ghiasvandian [a], Meysam Khoshavi [c], Seyed Mohammad Riahi [d], Ali Khanipour-Kencha [a,b], Marie Bakitas [e], J. Nicholas Dionne-Odom [f], Rachel Wells [g], Masoumeh Zakerimoghadam [a,*]

ENABLE CHF-PC-SG (SINGAPORE)-Chinese



Can we have similar quality of life outcomes by increasing access & acceptability?



Cancer mortality could be reduced by 25% with no new treatment advances *if only we applied our current knowledge to under-represented people with cancer!*

Freeman, H.P. **(1989).** Cancer in the socioeconomically disadvantaged. CA: A Cancer Journal for Clinicians, 39(5), 266–289.

Gupta, A., & Akinyemiju, T. **(2024).** Trends in Cancer Mortality Disparities Between Black and White Individuals in the US, 2000–2020. JAMA Health Forum, 5(1).


Palliative
Care
body
mind
spirit
dignity
comfort
chaplain
communication
autonomy
choices
Respect
disease
end of life
person-centered
empower
partnership
moral
support
celebrate
Resolution
nursing
pain management
decision-making
family
spiritual
care

Comprehensive Tele-palliative Care Re-writes Maebel's Story

- Maebel is 78 yo woman newly diagnosed inoperable glioblastoma. Palliative XRT & chemo recommended. Returns home to discuss with family.
- Because of distance from the cancer center, she & local son are enrolled in **telephonic palliative care program**. Maebel's nurse coach coordinates care with PCP & community resources. Helps her to learn to use goals & values to guide treatment choices. Son has support of **a lay navigator family support coach**.
- Maebel learns to have conversations with family about her wishes & **completes an advance directive identifying son as health care proxy.** She discusses the AD with MDs & family assuring all have copies & it's in her medical record.

Comprehensive Tele-palliative Care Re-writes Maebel's Story

- Maebel opts for **'palliative treatments' in local community for symptom**. Nurse coach organizes **video-consultation with cancer center palliative care specialist team**. They devise proactive home support & symptom management plan w/ emergency meds for common symptoms (e.g., seizures, headaches or pain.)

- She continues to participate in valued **church activities, congregation prays for her, provides meals, & helps with chores.**

- ~~She & family believe she will get "better" treatment at the "academic center" 50 miles away~~.

- Maebel & family have **video visits with local health care team** to "get on same page". They visit regularly to **reminisce (life review/legacy work).**

- ~~Oncology recommends 'palliative' chemo; Violet defers to MD advice.Family unable to visit due to transportation issues.~~

Comprehensive Tele-palliative Care Re-writes Maebel's Story

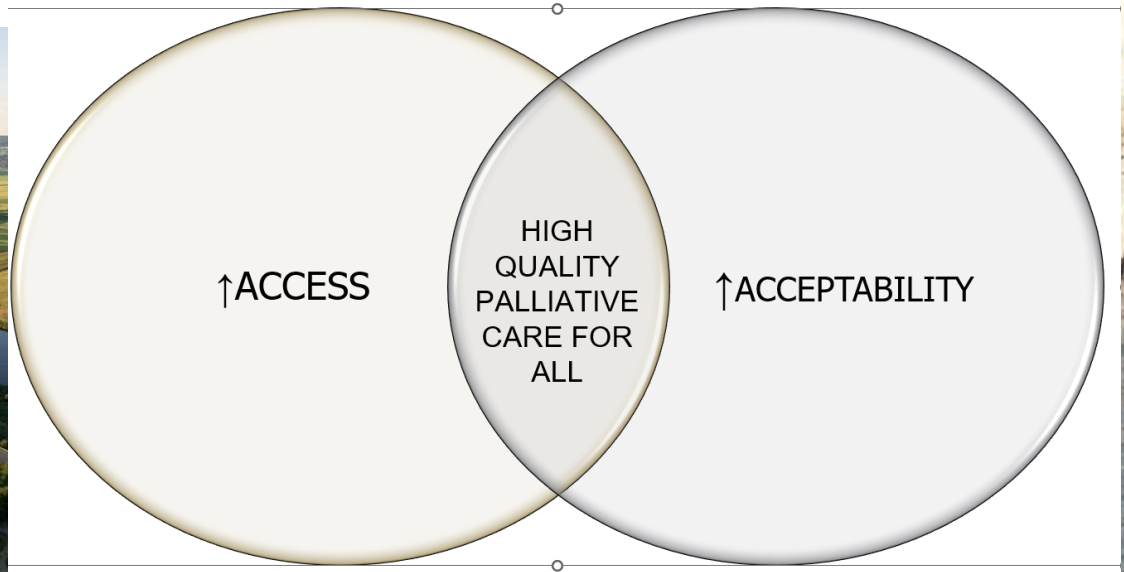
- Maebel becomes confused, reports headache, and starts vomiting.
- Family **contacts nurse coach who activates the emergency care plan to** provide rapid symptom relief & **home hospice**. Maebel continues to live comfortably at home. Family & church members gather to say good-byes as death nears.
- ~~You are caring for Maebel in ICU when she dies alone following lengthy resuscitation effort while MDs attempt to contact family for DNR.~~
- You feel satisfied knowing that Maebel's wishes were known & followed. During **bereavement calls 3 & 6 months** later, family continues to thank team for care & know mother is at peace. **They tell their friends & congregation about benefits of tele-palliative care & hospice** for their ill family members.

Take Home Messages

- Rural palliative care inequities result from a 'perfect storm' of older, sicker, poorer populations, medical mistrust, & few healthcare & palliative care resources.
- Realizing equitable, effective, & sustainable rural palliative care requires:

*increasing access

*culturally adapting care



Acknowledgements

3 decades of Dartmouth & UAB team members dedicated to relieving suffering, improving health equity while bringing love & joy to work every single day.

Thank you!

Please complete your evaluation

McGill