

Disclosure Statement

The author has no relevant
relationships to disclose

Unmuting Rural Voices: Towards Health Equity in Palliative Care

| 2

Serious Illness Care Research: Exploring
Current Knowledge, Emerging Evidence,
Future Directions
NASEM
November 2-3, 2023

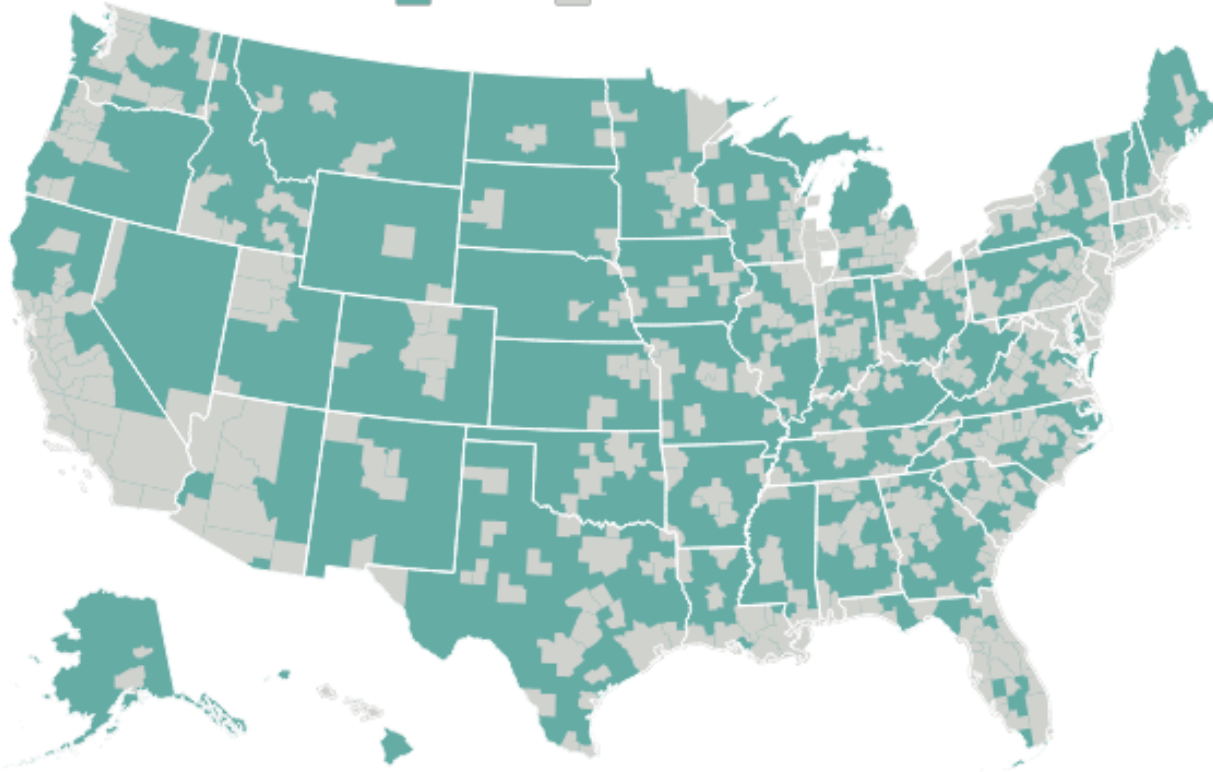
Marie Bakitas, DNSc, CRNP, FAAN
Associate Dean, Research & Scholarship, School of Nursing
Director, UAB Center for Palliative & Supportive Care
University Wide Interdisciplinary Research Center
University of Alabama at Birmingham



Areas classified as rural under the nonmetro definition



■ Rural ■ Not rural



Source: 2019 CBSA classification by the OMB

CENTER ON RURAL INNOVATION

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

46.7% [28million] are in the South



Rural America Has An Older, Sicker and Poorer Population

OLDER

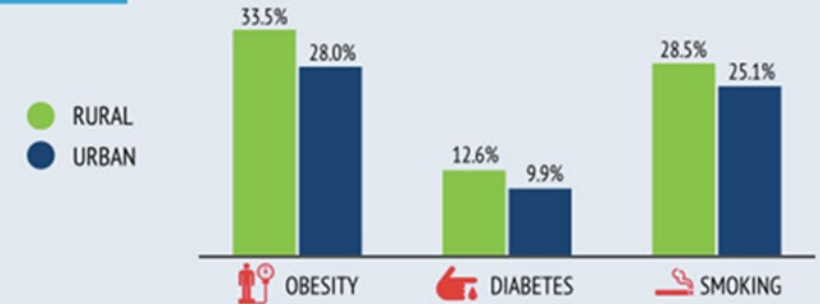
The median age of adults living in rural areas is greater than those living in urban areas.



18.4% of rural Americans are age 65+ versus **14.5%** of urban Americans.

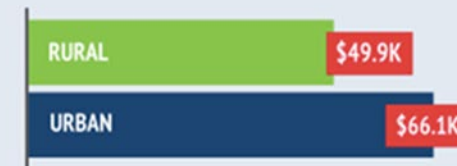
SICKER:

Rural areas have higher rates of several health risk factors and conditions.



POORER:

Nationally, rural households had lower median household income.



Below the Line

14.7% of the rural population is below the poverty line, compared to **11.3%** of the urban population.



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Rural America Has An Older, Sicker, And Poorer Population

NATIONAL INSTITUTE FOR HEALTH CARE MANAGEMENT (NIHCM)

“Perfect Storm” of Factors Creating Rural Palliative Care Inequities

- **Associations among rurality, persistent poverty, poor health outcomes**

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

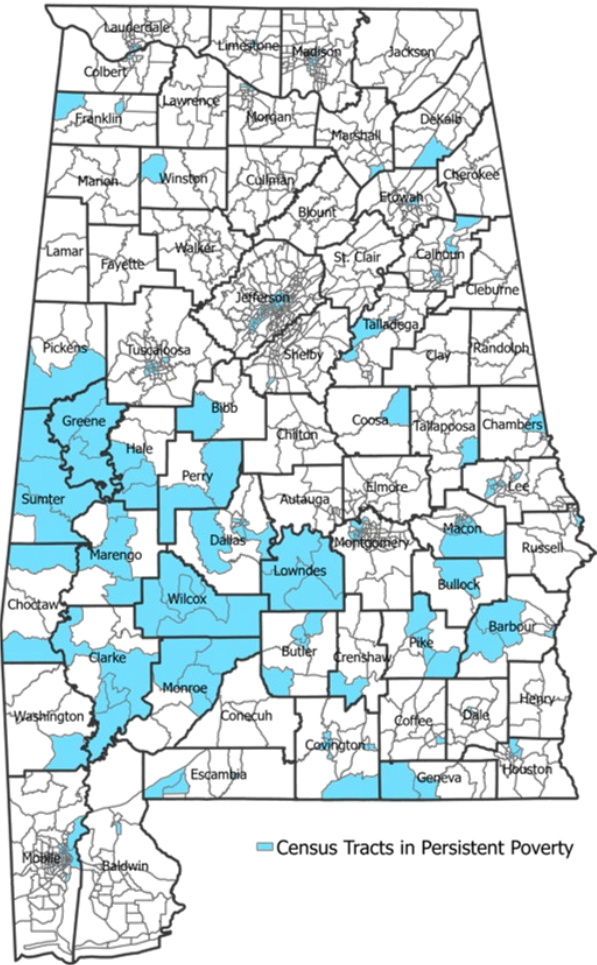
- **Medical mistrust from social injustice, racism, experimentation, broken treaties, ‘hit & run’, ‘one-size-fits-all’**

Alabama: Rurality, Persistent Poverty, Poor Health Outcomes

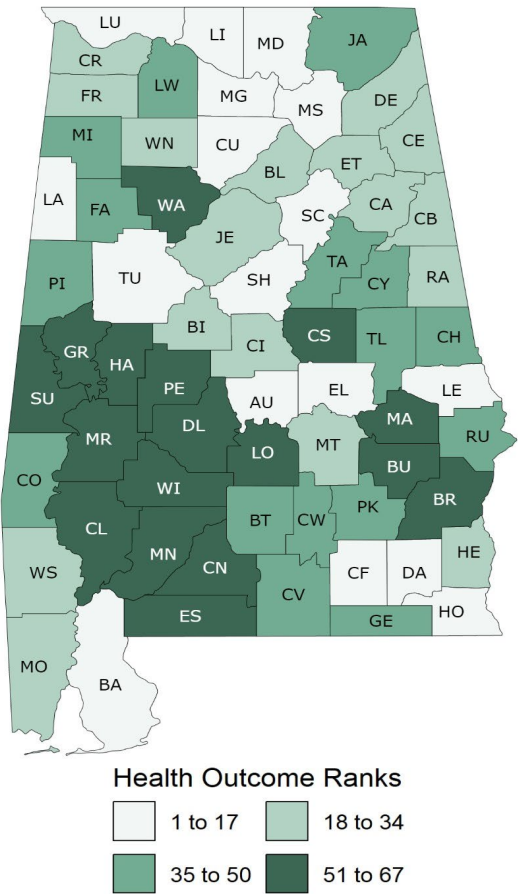
Alabama's Rural Landscape
as Defined by Office of Rural Health Policy



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



2023 Health Outcomes - Alabama



County Health
Rankings & Roadmaps
Building a Culture of Health, County by County

Medical Mistrust Among Rural Populations



TheUpshot
THE NEW HEALTH CARE

Did Infamous Tuskegee Study Cause Lasting Mistrust of Doctors Among Blacks?

Share full article



A doctor with a patient as part of the Tuskegee syphilis study.

By Aaron E. Carroll
June 17, 2016

JMA Journal of Ethics®
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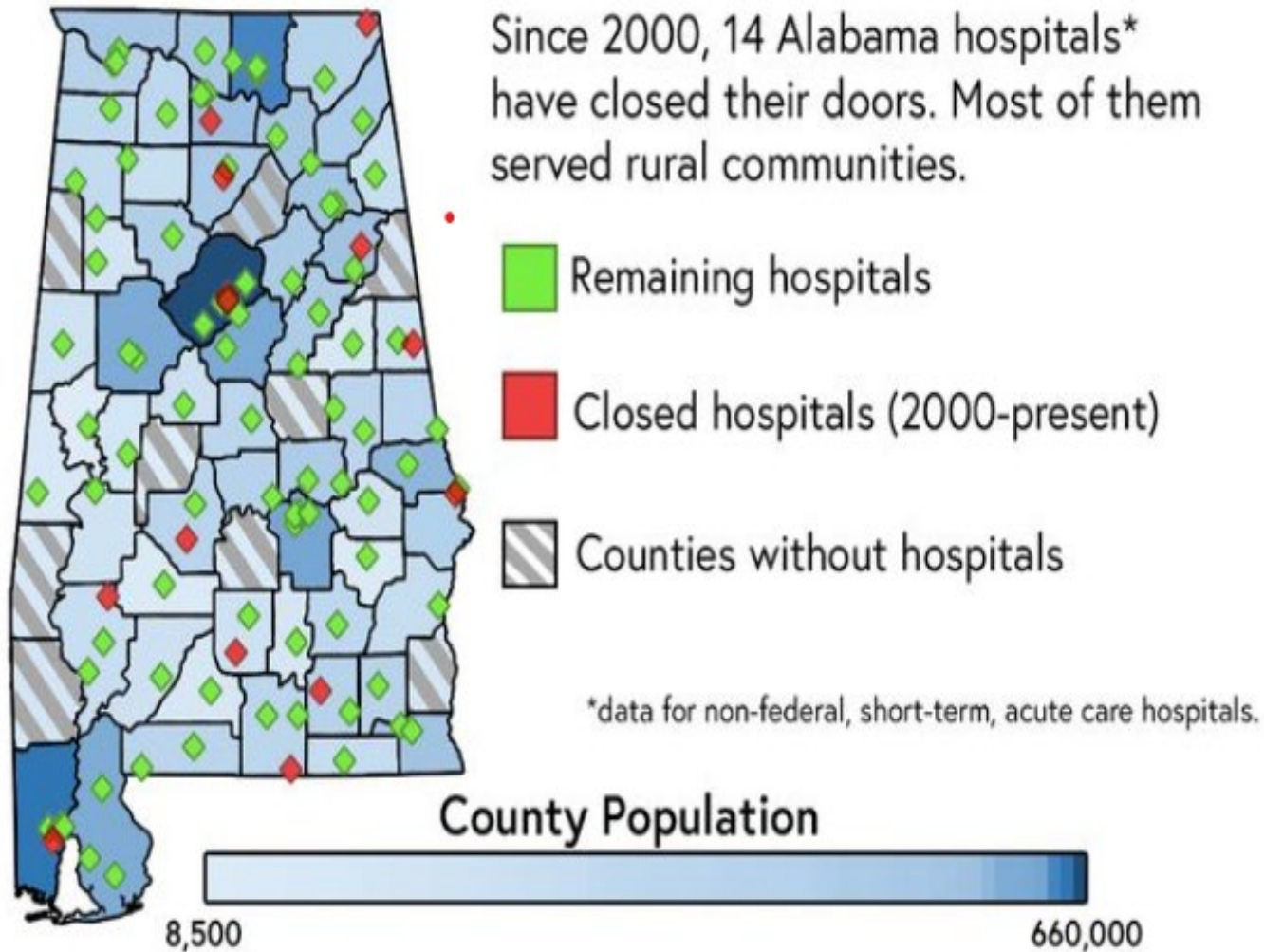
The Legacy of Henrietta Lacks



HONORING HENRIETTA

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

| 7

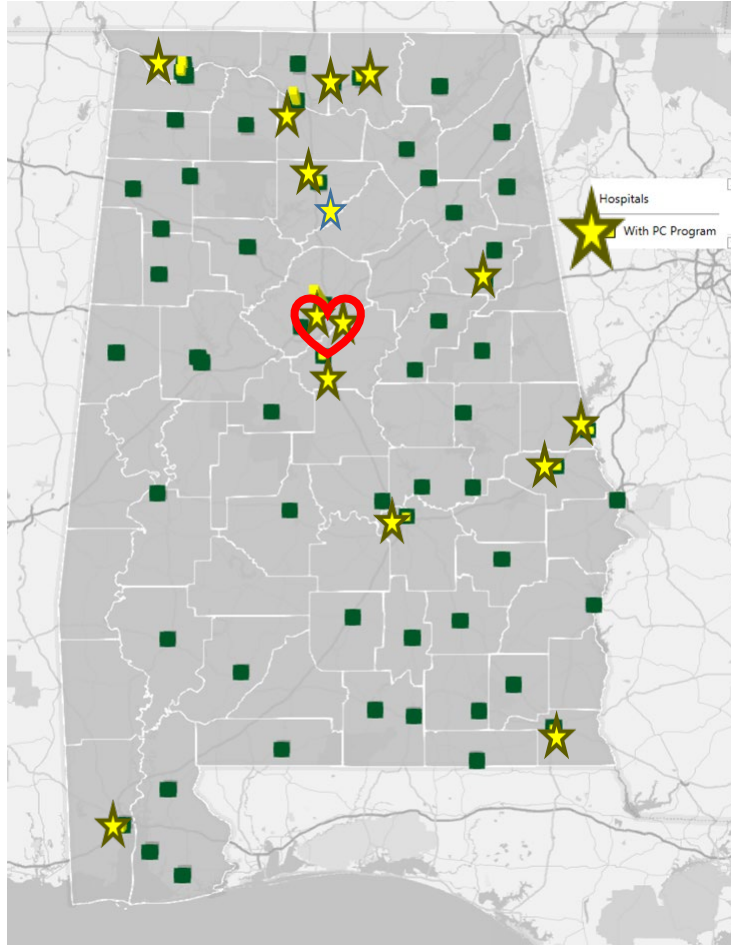


“You probably already know this—but Alabama is one of the states with the most hospitals at risk for closure in the next year. I think there are 28 rural hospitals—60 percent are at risk for closure”

-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.



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

**PICKENS COUNTY
MEDICAL CENTER**

Selected Rural Palliative Care Research & Lessons Learned*

Rural Palliative Care Studies

- 1999 & 2001 ENABLE (Educate, Nurture, Advise, Before Life Ends) – Cancer (Bakitas)
- 2008 ENABLE Expansion to Caregivers (Odom), 2012 Heart Failure (Wells), 2018 COPD (Iyer), 2018 International (Yang, Neo, Mirshahi)
- 2014 & 2020 ENABLE IV – (Bakitas, Zubkoff) EPC Implementation across cancer practices
- 2019-23 Community Tele-Pal Rural hospital (inpatient) videoconsultation & community engagement

Lessons Learned

- “If you build it, they will come” - except in the winter-- if it snows, ice, floods, there's a mountain, the car breaks down, can't afford transportation, too tired or ill, no family support, other family priorities (family, farming, caregiving, job/work responsibilities)
- Limited Connectivity--Landline Telephone Access--no or inconsistent cell/broadband availability
- Limited/No PC Workforce – Specialty trained--telephone coaches, teleconsultation → lay advisors

Hub & Spoke Model → Central expertise & Community-based primary palliative care-trained (Lay) work force

* Supported by: NINR, NCI, NIA, NPCRC, ACS, PCORI

Beyond Broadband—All about Culture

11

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, CRNP¹; Kristen Allen Watts, PhD¹; Emily Malone, MPH¹; J. Nicholas Dionne-Odom, PhD, RN¹; Susan McCammon, MD¹; Richard Taylor, DNP, CRNP¹; Rodney Tucker, MD¹; and Ronit Elk, PhD¹



- **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

12

- **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 McCommon (right), a surgeon and palliative medicine physician at the University of Alabama at Birmingham, regularly visits patients such as Janice Bass, shown with her dog, Abbey, to manage treatment and support advance care planning.

DOI: 10.1377/hlthaff.2019.01470

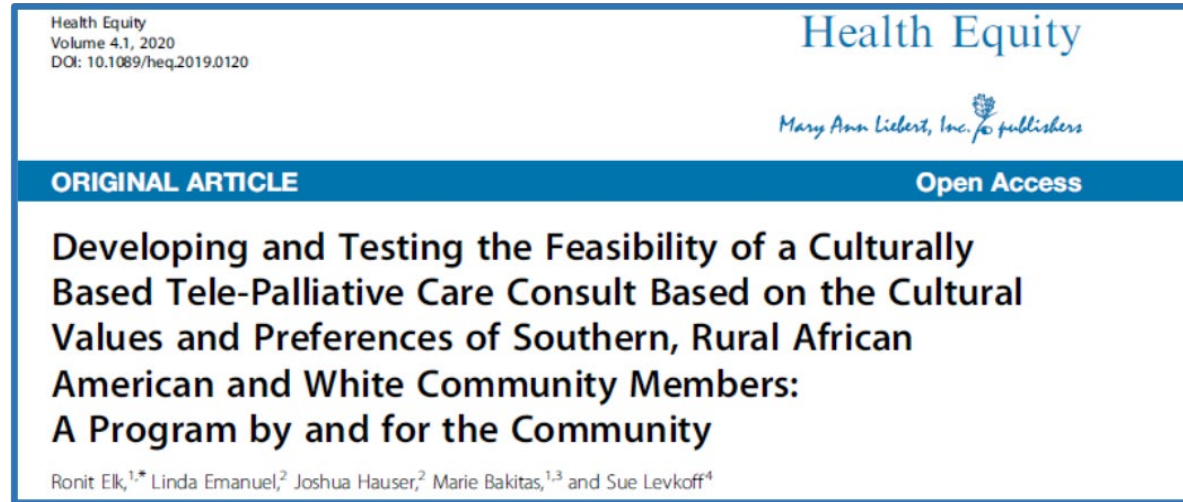
Bringing Palliative Care To Underserved Rural Communities

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

BY CHARLOTTE HUFF



Tailoring Palliative Care to Rural South Black & White Communities



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.

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>

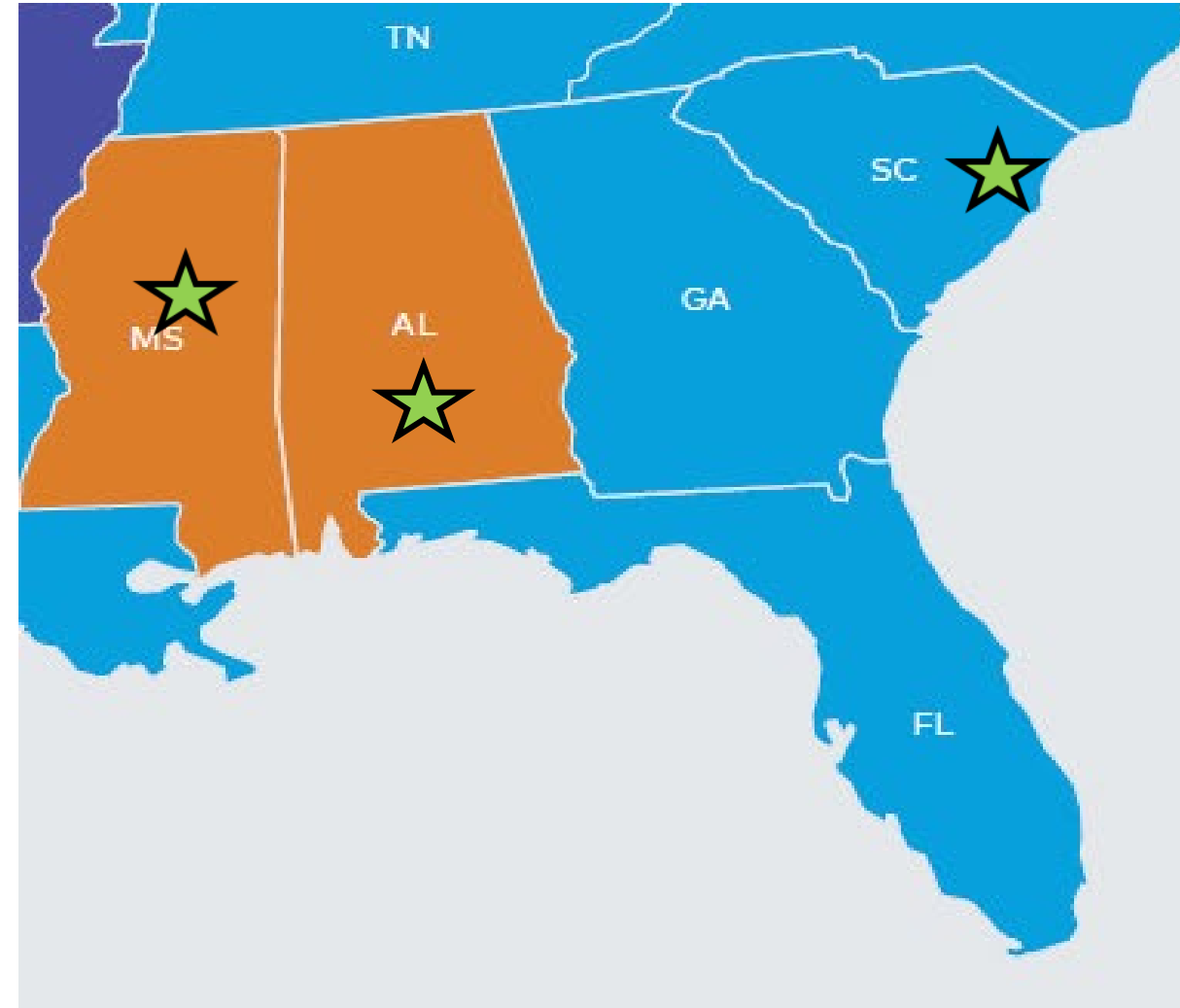
Trials

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 Watts¹, Shena Gazaway², Emily Malone¹, Ronit Elk^{1,3}, Rodney Tucker^{1,3}, Susan McCammon^{3,4}, Michele Goldhagen⁵, Jacob Graham⁶, Veronica Tassin⁷, Joshua Hauser⁸, Sidney Rhoades⁹, Marjorie Kagawa-Singer¹⁰, Eric Wallace¹¹, James McElligott¹², Richard Kennedy¹ and Marie Bakitas^{13*} 



CAGs culturally tailored study materials & recruitment procedures to their community.

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 Gazaway¹, Marie Bakitas², Felicia Underwood³, Christiana Ekelem³, Marlee Duffie⁴, Sheila McCormick⁵, Vantrice Heard⁴, Audrey Colvin⁶, Ronit Elk³

Affiliations + expand

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

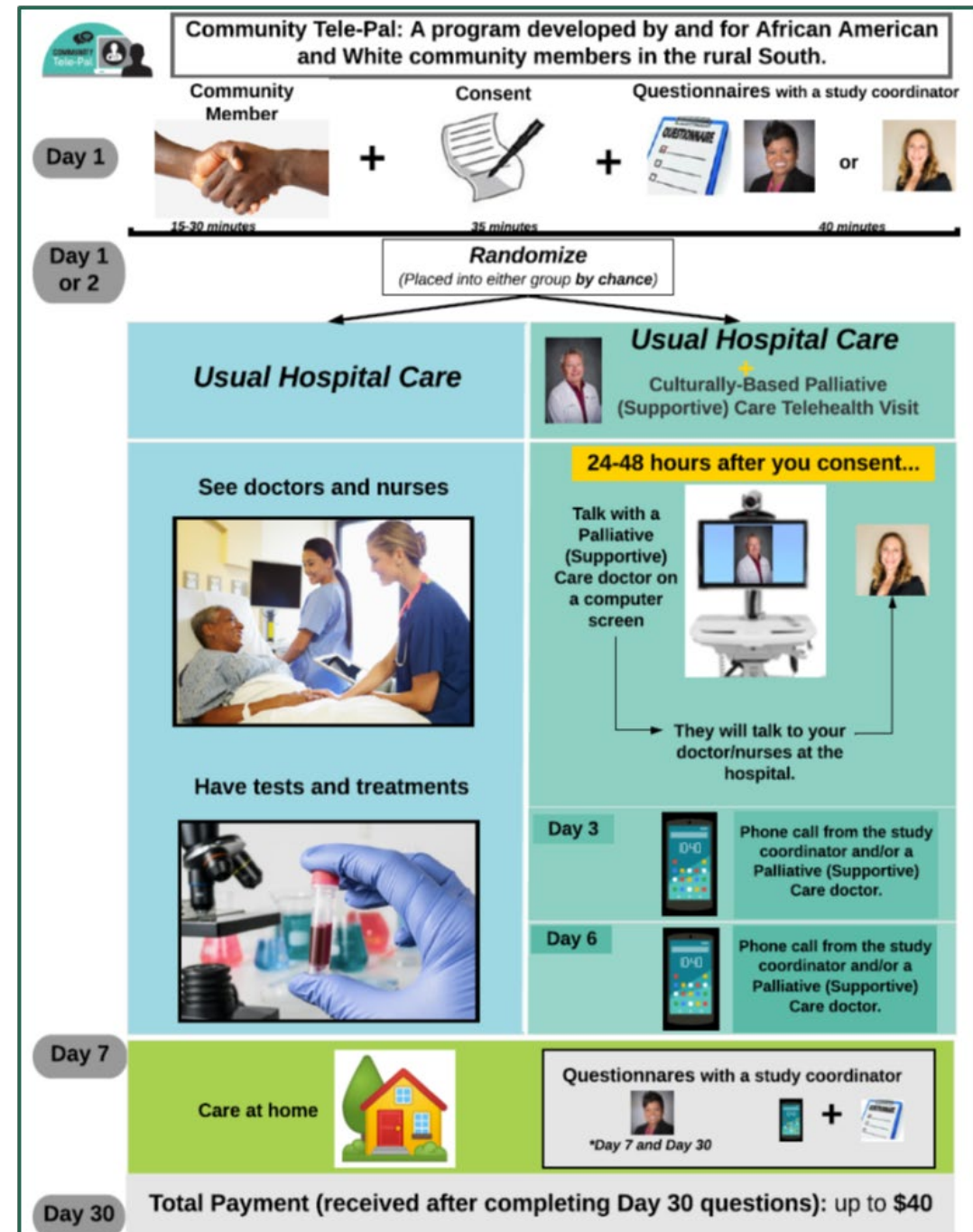
FULL TEXT LINKS

ELSEVIER
FULL-TEXT ARTICLE

ACTIONS

Cite

Collections





Conclusions & Key Take Aways

17

Rural PC inequities result from a 'perfect storm' of older, sicker, poorer populations, medical mistrust, & few healthcare & PC resources.

Research and resources should...

- *engage with & hear the unique voices of rural communities,
- *recognize limited or absent health care foundation &
- *be creative in developing PC workforce & resources.

Practice/QI Exemplars in Developing Rural Palliative Care

Veterans Health Administration- **Advanced Illness/Palliative Care (AIPC)**- home visits, telehealth

2001

Resolution Care (Fratkin) – home visits, telehealth
<https://doctorpreneurs.com/michael-fratkin-founder-resolutioncare>

2014

Community-based Palliative Leadership Centers- Center to Advance Palliative Care –
<https://www.capc.org/palliative-care-community/>

2017

2008

Community-based Rural Palliative Care Networks & Toolkit (Stratis Health)-
(<https://stratishealth.org/toolkit/palliative-care-resource-center/>)

- 2017-2020 WA, MN, ND, WI-QI Rural PC Network Project

2017

Project ECHO - (Extension for Community Healthcare Outcomes) – 4 Seasons Compassion for Life