

Bringing Primary Palliative Care to Rural Alabama: a utopia or reality?

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Disclosures

All three presenters declare
no financial conflicts to disclose

Objectives

1. Define Primary Palliative Care (PPC) and explain its importance for the global health agenda (Markaki)
2. Understand Alabama's health outcomes, health care needs and resources (Selleck)
3. Identify challenges and resources available to implementing PPC in rural Alabama (Selleck/Beasley)
4. Describe successful models for teaching and integrating PPC into a rural health system (Beasley)

Public health strategy for Palliative Care (1)

Integrating palliative care into a country's health care system (WHO, 1990)

- palliative care as a key pillar of comprehensive cancer control

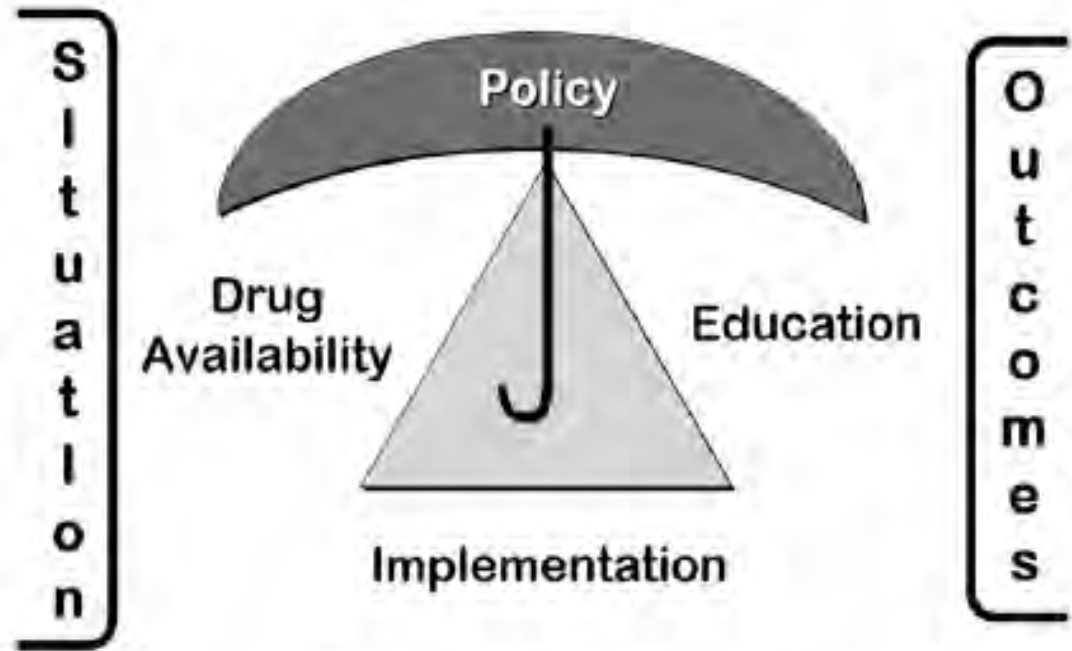


Fig. 1. WHO Public Health Model.

Public health strategy for Palliative Care (2)



Fig. 2. Detailed WHO Public Health Model.

Primary Palliative Care (PPC)

Provided by individuals and organizations who are not part of a specialist palliative care team.

- *In the community*
- *In hospitals* (by general staff, and disease specific teams)
- A wise combination of generalist and specialist PC
➔ a more sustainable and cost-effective approach



Fig. 3. "Palliative Care for All."

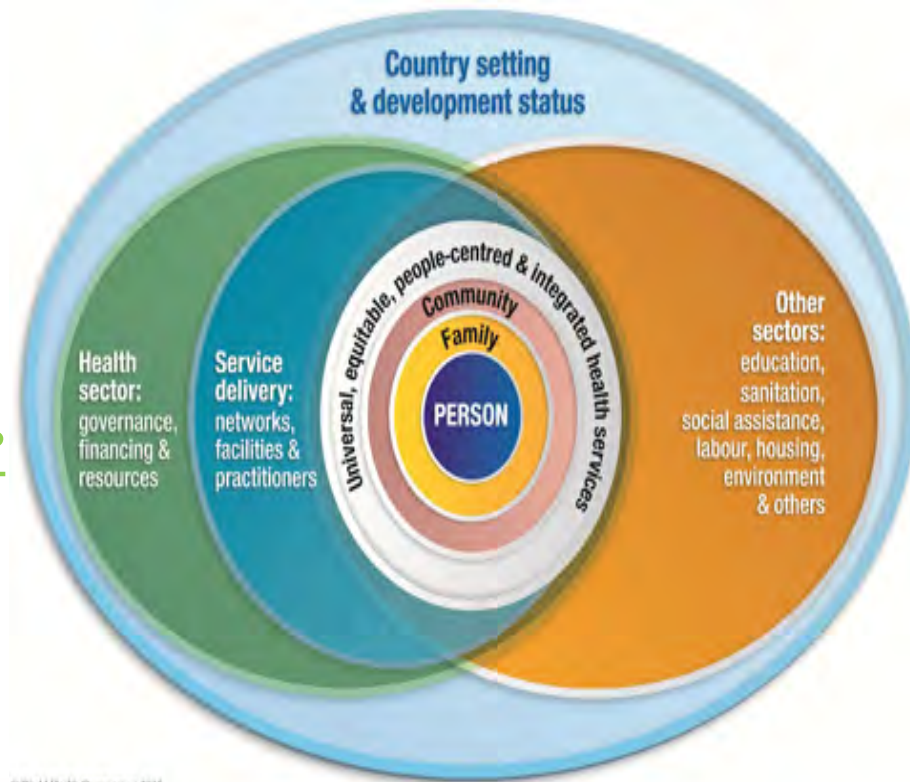
PPC Fundamental Principles

- Integral part of comprehensive care and support for: people living with HIV/AIDS (PLWHA) and cancer patients
- Provided in a continuum of care from: diagnosis of an incurable disease until the end of life
- To ensure population coverage it should be provided in: health institutions, home, and community-based organizations

	FROM	Change TO / AND	Comments TAG Survey: Combine advanced and terminal
Perspective for planning	Palliative care services	+ Palliative care approach everywhere	Palliative approach in all settings - with specialist palliative care services for complex cases
	Specialist services	+ Actions in all settings	
	Institutional approach	+ Community approach	Inclusive of all levels of care with emphasis on community approach
	Services' approach	+ Population & District	
	Individual service	+ District approach	A global population vision is needed

PPC within the framework of Integrated People-Centred Health Services (IPCHS)

“[...] services managed and delivered so that people receive a continuum of health promotion, disease prevention, diagnosis, treatment, disease-management, rehabilitation **and palliative care services**, coordinated across the different levels and sites of care within and beyond the health sector, and according to their needs throughout the life course.”



World Health Organization. (2017) Framework on integrated people-centred health services.

<http://www.who.int/servicedeliverysafety/areas/people-centred-care/framework/en/>

Relevance to global health agenda (1)

- To remedy access gaps, a **universally accessible Essential Package** has been recommended (Lancet Commissions Report, 2018)
- LMICs can improve the welfare of disadvantaged people at modest cost by:
 - Publicly financing and fully integrating the Essential Package into NHS, as part of **universal health coverage**

Alleviating the access abyss in palliative care and pain relief— an imperative of universal health coverage: the Lancet Commission report



Felicia Marie Knaut, Paul E Farmer*, Eric L Krakauer*, Liliana De Lima, Afshan Bhaddia, Xiaoxiao Jiang Kwete, Héctor Anreola-Omelas, Octavio Gómez-Dantés, Natalia M Rodríguez, George A O Alleyne, Stephen R Connor, David J Hunter, Diiderik Lahman, Lukas Radbruch, María del Rocío Sáenz Madrigrál, Rifat Atun†, Kathleen M Foley†, Julio Frenk†, Dean T Jamison†, M R Rajagopal†, on behalf of the Lancet Commission on Palliative Care and Pain Relief Study Group†

Executive Summary

In agonising, crippling pain from lung cancer, Mr S came to the palliative care service in Calicut, Kerala, from an adjoining district a couple of hours away by bus. His body language revealed the depth of the suffering.

We put Mr S on morphine, among other things. A couple of hours later, he surveyed himself with disbelief. He had neither hoped nor conceived of the possibility that this kind of relief was possible.

Mr S returned the next month. Yet, common tragedy befell patient and caregivers in the form of a stock-out of morphine.

Mr S told us with outward calm, "I shall come again next Wednesday. I will bring a piece of rope with me. If the tablets are still not here, I am going to hang myself from that tree". He pointed to the window. I believed he meant what he said.

Stock-outs are no longer a problem for palliative care in Kerala, but throughout most of the rest of India, and indeed our world, we find near total lack of access to morphine to alleviate pain and suffering.

Dr M R Rajagopal, personal testimony

Poor people in all parts of the world live and die with little or no palliative care or pain relief. Staring into this access abyss, one sees the depth of extreme suffering in the cruel face of poverty and inequity.

The abyss is broad and deep, mirroring relative and absolute health and social deprivation. Of the 298.5 metric tonnes of morphine-equivalent opioids distributed in the world per year (average distribution in 2010–13), only 0.1 metric tonne is distributed to low-income countries.¹ The amount of morphine-equivalent opioids distributed in Haiti is 5 mg per patient in need of palliative care per year, which means that more than 99% of need goes unmet. By contrast, the annual distribution of morphine is 55 000 mg per patient in need of palliative care in the USA and more than 68 000 mg per patient in need of palliative care in Canada—much more than is needed to meet all palliative care and other medical needs for opioids on the basis of estimates of the Commission (figure 1).

The fact that access to such an inexpensive, essential, and effective intervention is denied to most patients in low-income and middle-income countries (LMICs) and in particular to poor people—including many

poor or otherwise vulnerable people in high-income countries—is a medical, public health, and moral failing and a travesty of justice. Unlike so many other priorities in global health, affordability is not the greatest barrier to access, and equity-enhancing, efficiency-oriented, cost-saving interventions exist.

The global health community has the responsibility and the opportunity to close the access abyss in the relief of pain and other types of suffering at end-of-life and throughout the life course, caused by life-limiting and life-threatening health conditions. However, unlike many other essential health interventions already identified as priorities, the need for palliative care and pain relief has been largely ignored, even for the most vulnerable populations, including children with terminal illnesses and those living through humanitarian crises, and even in the Sustainable Development Goals (SDGs).² Yet palliative care and pain relief are essential elements of universal health coverage (UHC).

Several barriers explain this neglect: the focus of existing measures of health outcomes—major drivers of policy and investment—on extending life and productivity with little weight given to health interventions that alleviate pain or increase dignity at the end of life;³ ophophobia, which refers to prejudice and misinformation about the appropriate medical use of opioids;⁴ the focus, in medicine, on cure and extending life and a concomitant neglect of caregiving and quality of life near death;⁵ limitations on patient advocacy due to the seriousness of illness; the focus on preventing non-medical use of internationally controlled substances without balancing the human right to access medicines to relieve pain;^{6,7} and the global neglect of non-communicable diseases, which account for much of the need for palliative care.⁸

Global health is devoid of the investments, interventions, and indicators that are essential to ensure universal access to safe, secure, and dignified care at the end of life or to the palliation of pain and suffering. With this Report, we aim to remedy these limitations by: (1) quantifying the heavy burden of serious health-related suffering (SHS) associated with a need for palliative care and pain relief (section 1); (2) identifying and costing an Essential Package Of Palliative Care And Pain Relief Health Services (the Essential Package) that would alleviate this burden (section 2); (3) measuring the unmet need for one of the most essential components of the

Lancet 2018; 391: 1391–454

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This online publication has been corrected. The corrected version first appeared at the lancet.com on March 9, 2018.

See Comment page 1318

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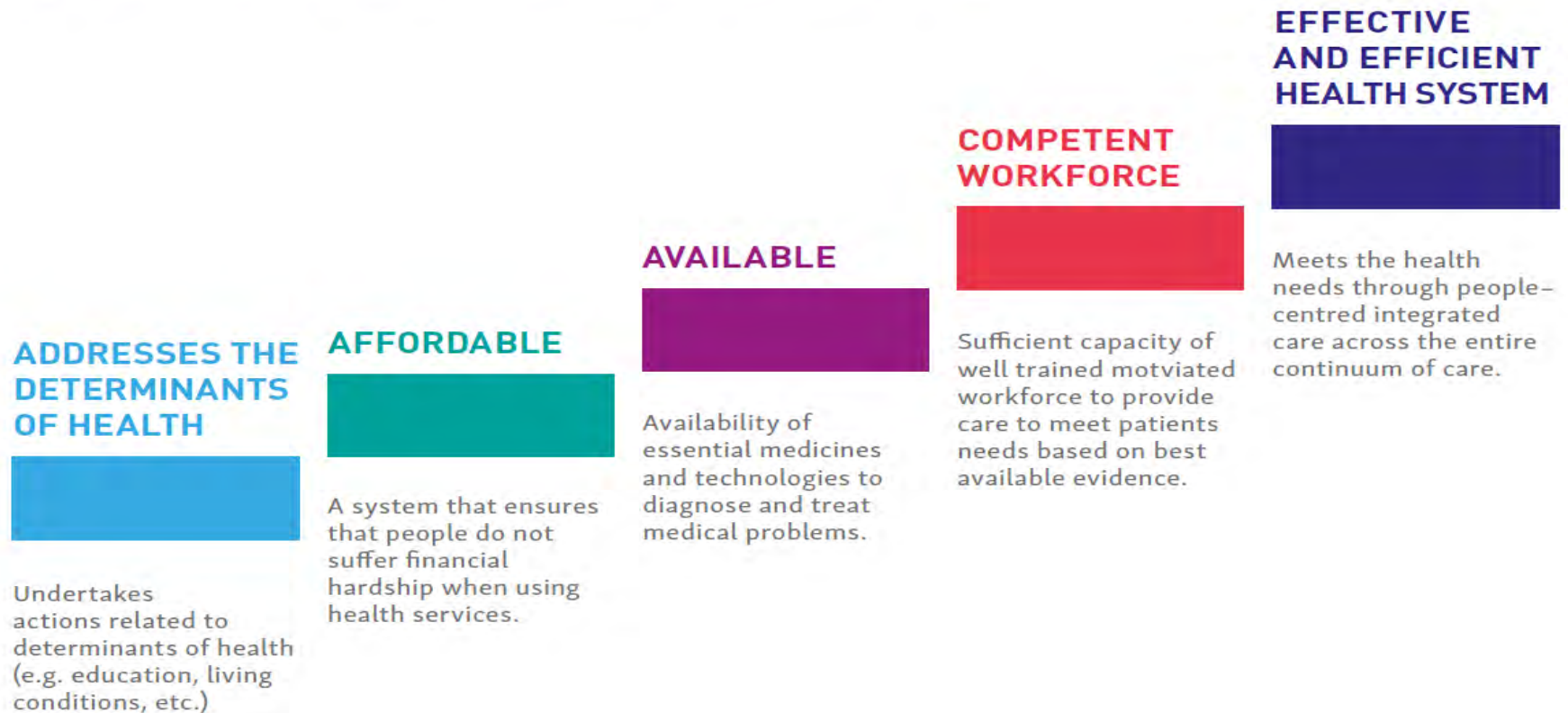
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Relevance to global health agenda (2)

Figure 9: Factors required to achieve Universal Health Coverage^{7, 82}



Operationalizing PPC – global efforts (1)



EAPC

TOOLKIT FOR THE DEVELOPMENT OF PALLIATIVE CARE IN THE COMMUNITY

PURPOSE OF THIS DOCUMENT

This resource is being developed by the EAPC in liaison with WONCA to help support and guide individuals and organisations in Europe and possibly worldwide seeking to further develop palliative care services in primary care settings. The principles outlined in the [EAPC Prague Charter](#) and particularly that access to palliative care as a human right underpins this work. IN 2014 the WHO has recommended that palliative care should be integrated in primary care services, and this toolkit gives practical guidance on the steps required.

WHY IS DEVELOPING PALLIATIVE CARE IN THE COMMUNITY IMPORTANT?

Murray SA, et al. (2014). Promoting palliative care in the community: Production of the primary palliative care toolkit by the European Association of Palliative Care Taskforce in primary palliative care. *Palliat Med* 29, 101-111.



Operationalizing PPC - global efforts (2)

Review Article

Cancer and Palliative Care in the United States, Turkey, and Malawi: Developing Global Collaborations

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Grant et al. *BMC Palliative Care* 2011, **10**:8
<http://www.biomedcentral.com/1472-684X/10/8>



RESEARCH ARTICLE

Open Access

Palliative care making a difference in rural Uganda, Kenya and Malawi: three rapid evaluation field studies

Liz Grant^{1*}, Judith Brown², Mhoira Leng³, Nadia Bettega⁴ and Scott A Murray¹

PALLIATIVE CARE: HOW TO EXPAND ACCESS IN THE CARIBBEAN

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Operationalizing PPC - global efforts (3)

CASE STUDY: Innovative models for palliative care in rural India

Contributor: Barbara Pesut, Brenda Hooper, Marnie Jacobsen, Barabra Nielsen, Miranda Falk, Brian P.O'Connor

Country: India

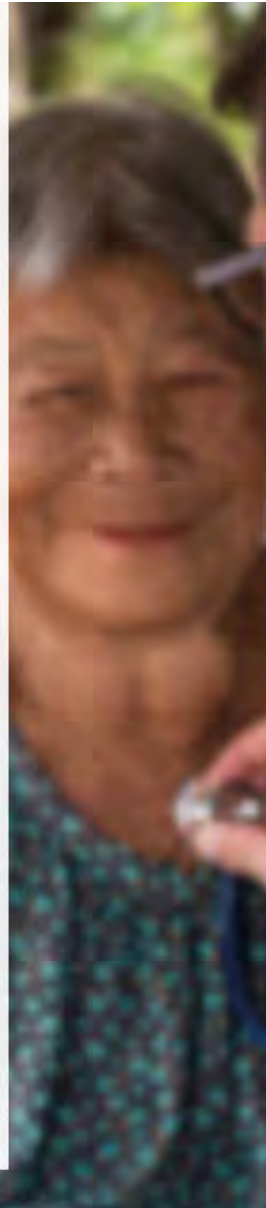
A recent pilot of a nurse-led palliative care service in India has sought to address the challenge of the provision of palliative care services to people living in rural India through a community capacity building approach. People with advanced chronic disease received home visits by a nurse who performs a supportive navigation role. Patients were seen by the nurse either weekly or biweekly with a variety of services being provided for a wide range of issues. Problems included family conflict, community isolation, financial challenges, troubling symptoms and mobility issues. The nurse navigator addressed these problems over time by bridging the gaps between health and social care.⁹³

The primary interventions by nurses were education about the management of symptoms and psychosocial support for the emotional challenges of living with advanced illness. They would also assist people to comprehend the health care information and make decisions about possible treatments to manage the symptoms of the disease. The domains of supportive care provided by the nurse navigators were extremely diverse ranging from disease management; spiritual and physical care; advanced care planning; psychological support; and social support.⁹³

It is estimated that 34 million people in India would benefit from palliative care, but less than 1% of these people have access to it.⁹⁴ Many people with late stage conditions have 'heavy' symptom burden and are at risk of increasing social isolation. Patients and family members are often unaware of the health and social services available to them in their community. The lack of appropriate and suitable support for palliative care has terrible consequences to people's final stages of life. Rurality also adds a layer of complexity to this challenging situation. Rural health services are often limited and inaccessible. This is mostly due to skilled workforce shortages.⁹³

As a result of this service, it is believed that there is reduced emergency room usage, hospital admissions and primary care physician visits. Patient satisfaction is higher, and more people can choose to die at home. The service also meant that the nurse navigator was able to assist clients identify available benefits and cost-effective alternatives to care, thereby creating cost savings to the family.⁹³

Whether implemented independently, or partnered with volunteers, a nurse-led navigation service can meet the unique needs of rural communities by enhancing support and access in the face of limited health care resources.⁹³



- Nurse-led pilot PC service
- Community capacity building approach
- Nurse navigator bridged the gaps between health and social care

ICN. Nurses - a voice to lead: health is a human right (2018)
<https://2018.icnvoicetolead.com/resources/>

Building Leaders to Promote Education, Practice, and Advocacy (1)

- PC specialty has limited resources
- Pre-licensure nsg students, educated to provide PPC, can fill that gap
- An innovative online nursing curriculum that prepares students with essential PPC nursing knowledge and skills

Modules

Introduction to Palliative Nursing
Communication in Palliative Nursing
Pain Management
Symptom Management
Loss, Grief, and Bereavement
Final Hours of Life

Nurse Educator

Nurse Educator
Vol. 43, No. 5, pp. 242-246
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An Innovative End-of-Life Nursing Education Consortium Curriculum That Prepares Nursing Students to Provide Primary Palliative Care

Betty Ferrell, PhD, RN, FAAN, MA, FPCN, CHPN
Polly Mazanec, PhD, RN, ACNP-BC, AOCN, FPCN, ACHPN • Pam Malloy, MN, RN, FAAN, FPCN
Rose Virani, MHA, RNC, OCN, FPCN

Research has demonstrated that patients facing serious, life-limiting illnesses and their families benefit from receiving palliative care. Increasingly, however, specialty palliative care has limited resources. Prelicensure nursing students who are educated to provide primary palliative care to patients with serious illness and at the end of life can fill that gap. This article describes the development and implementation of an innovative online nursing curriculum that prepares students with essential primary palliative nursing knowledge and skills.

Keywords: curriculum; End-of-Life Nursing Education Consortium (ELNEC); hospice and palliative nursing; nursing students; palliative care



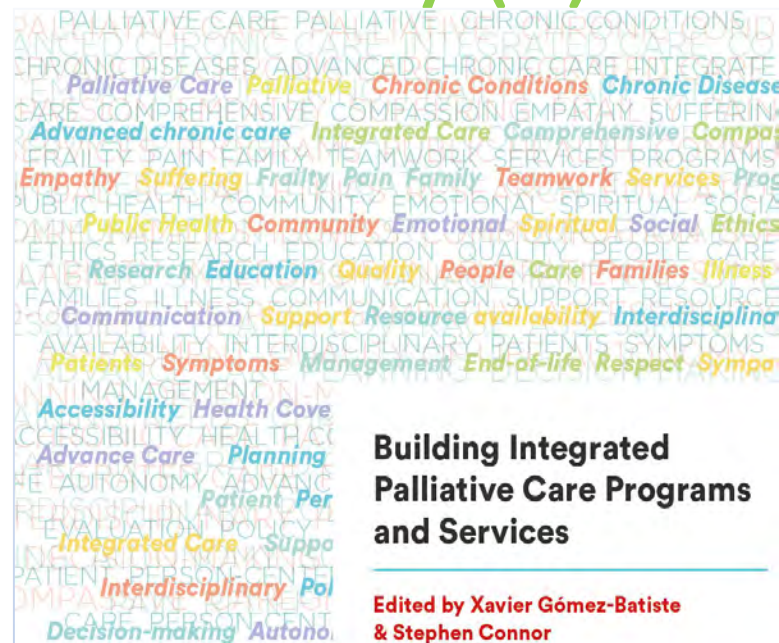
ELNEC

END-OF-LIFE NURSING EDUCATION CONSORTIUM

Advancing Palliative Care

Building Leaders to Promote Education, Practice, and Advocacy (2)

- The Global State of Palliative Care (July 2018, Melbourne Australia)
An overview of ELNEC curricula, emphasis on module design and teaching/learning strategies
(ELNEC-Core, Pediatrics, Geriatrics, Critical Care, Advanced Practice Registered Nursing, and ELNEC-International)
- Strategies to improve programs and services



Building Integrated Palliative Care Programs and Services

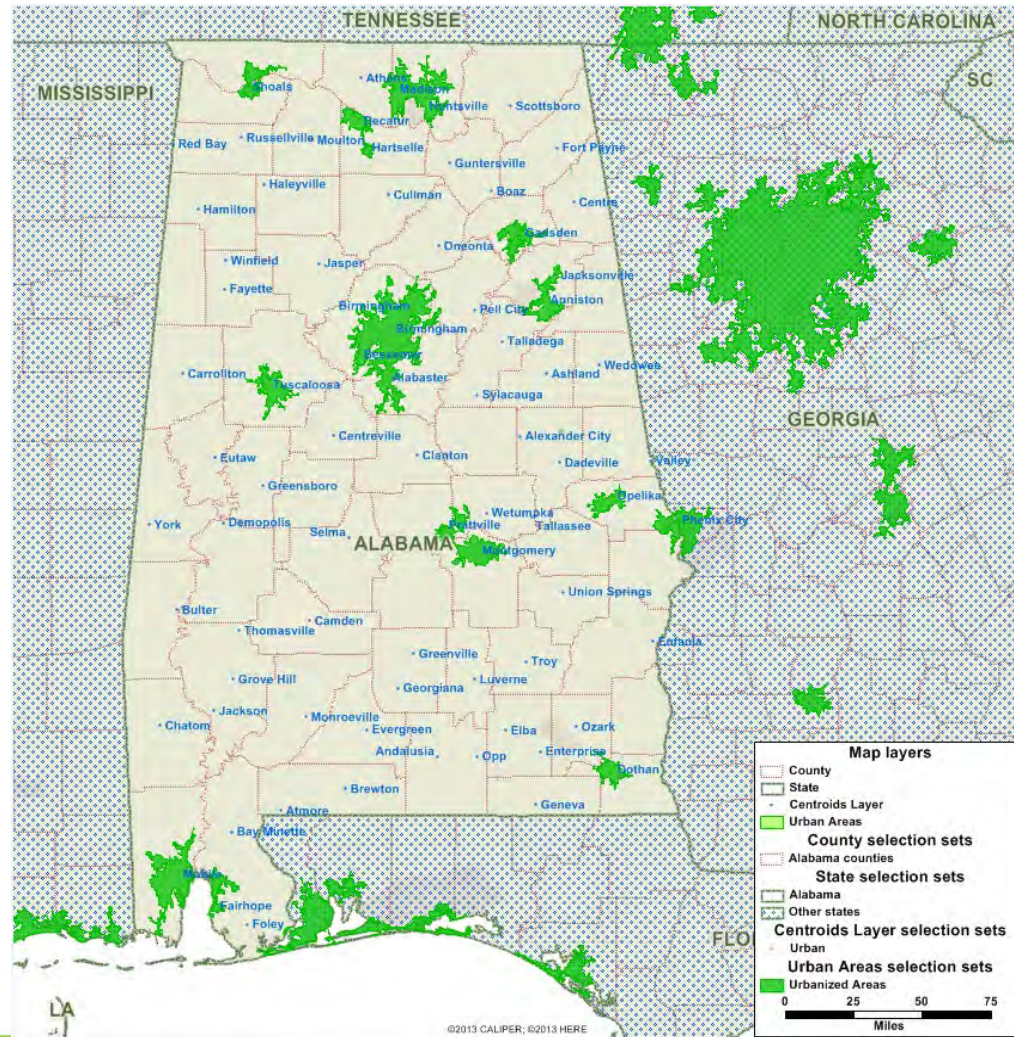
Edited by Xavier Gómez-Batiste & Stephen Connor

Building Integrated Palliative Care Programs and Services. Eds Xavier Gomez-Batiste & Stephen Connor (2017) Catalonia, Spain.

Snapshot of Alabama's health

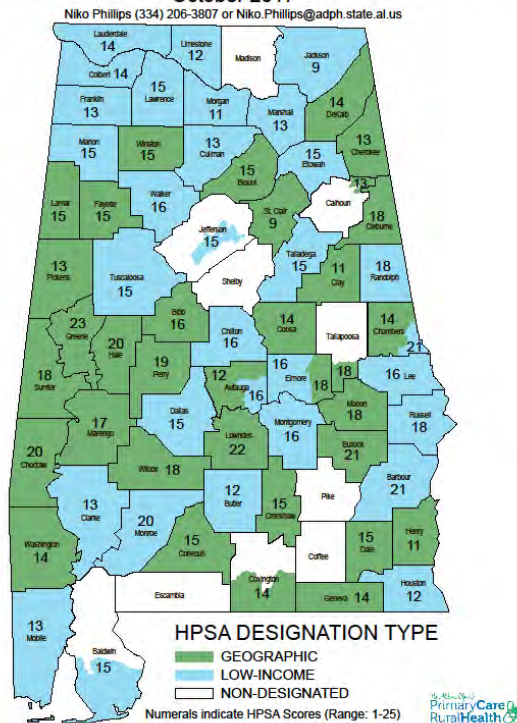
- Overall health ranking among poorest in U.S.
- Alabama ranked 47th in 2017 and 2016, 46th in 2015, 43rd in 2014, 47th in 2013, 45th in 2012
- Largely rural state (54 of 67 counties)
- Lack of access to healthcare is a major factor
- Shortage of health professionals in the state
- All 67 counties have MUA/MUP designations
- Significant primary care, dental and mental health HPSA designations

Urbanized areas of Alabama



Alabama's Primary Care Health Professional Shortage Areas (HPSA)

Primary Care Health Professional Shortage Areas
October 2017

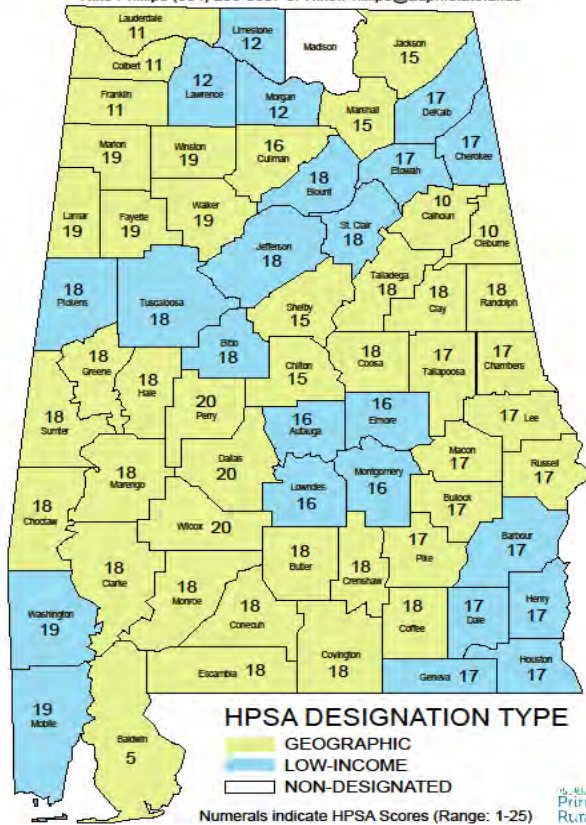


**62 of 67 counties
have primary care
HPSA
designations:
51 whole county
11 partial county**

Alabama's Mental Health & Dental Health HPSAs

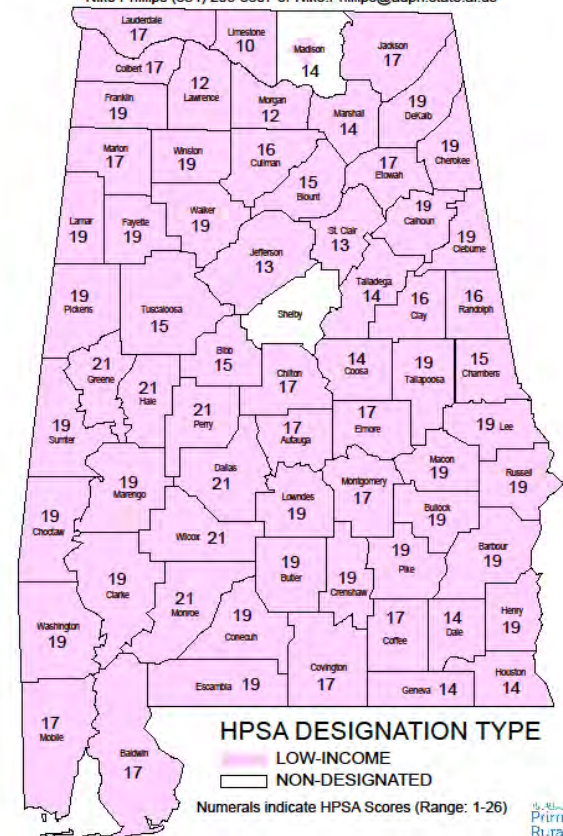
Mental Health Professional Shortage Areas
October 2017

Niko Phillips (334) 206-3807 or Niko.Phillips@dph.state.al.us



Dental Health Professional Shortage Areas
October 2017

Niko Phillips (334) 206-3807 or Niko.Phillips@dph.state.al.us



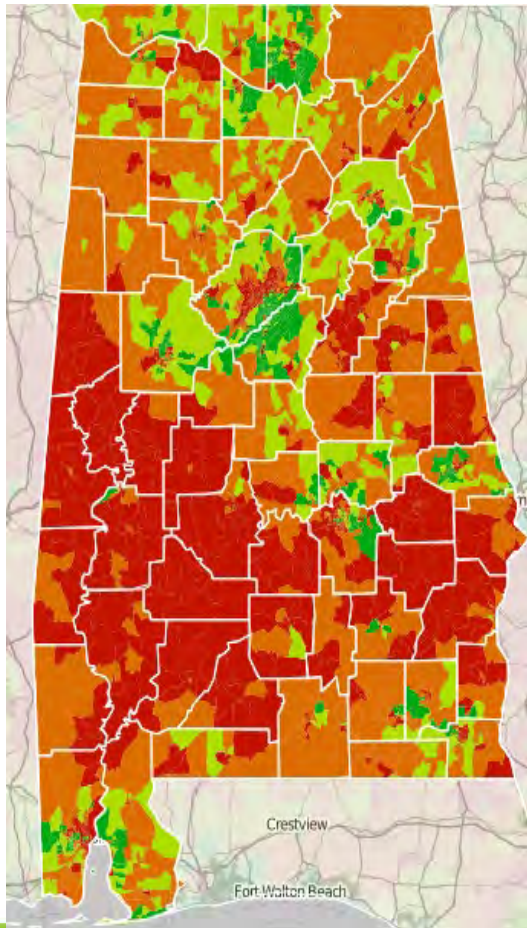
Characteristics of rural Alabama

- Older
- Less formal education
- Greater racial / ethnic diversity
- Less wealthy
- Poorer health status
- Less health insurance
- Higher unemployment
- Less available transportation
- Many rural areas are shrinking in population

Access to healthcare is a challenge in rural Alabama

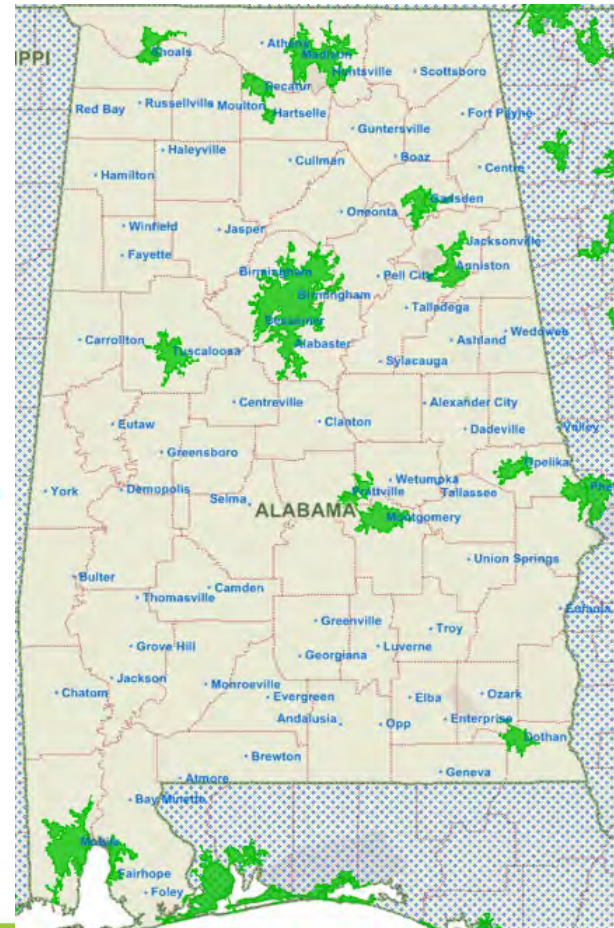
- 8 rural counties do not have hospitals; many others on the verge of closing.
- 13 rural Alabama counties do not have a dialysis clinic.
- Deaths from heart disease are 50-60% higher than the U.S.
- Deaths from cancer are 24-30% higher than the U.S.
- Deaths from strokes are 40-50% higher than the U.S.

Health literacy in rural Alabama

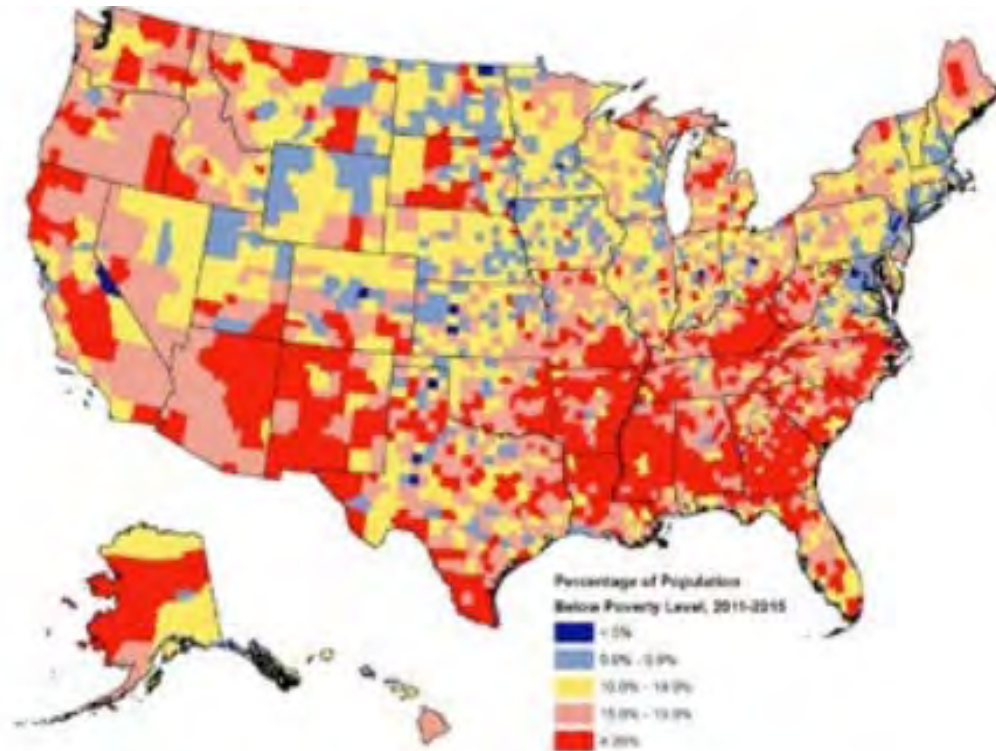


Health Literacy Levels

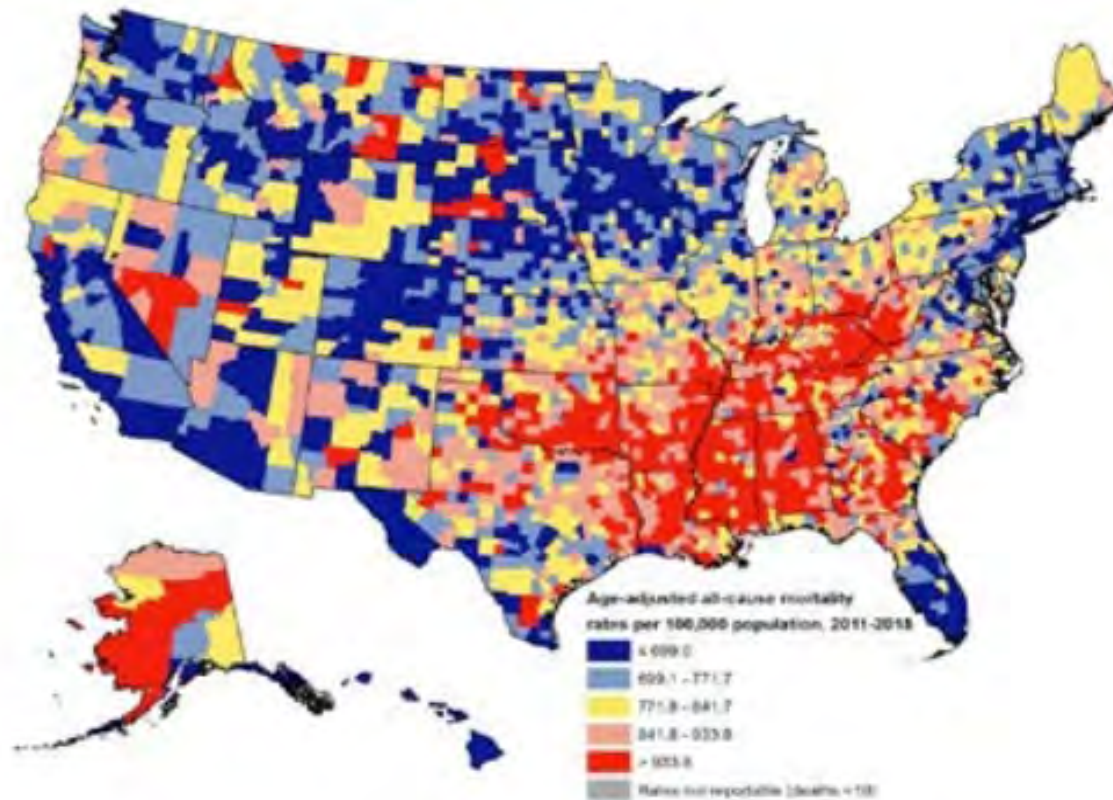
- Quartile 4 (highest)
- Quartile 3
- Quartile 2
- Quartile 1 (lowest)



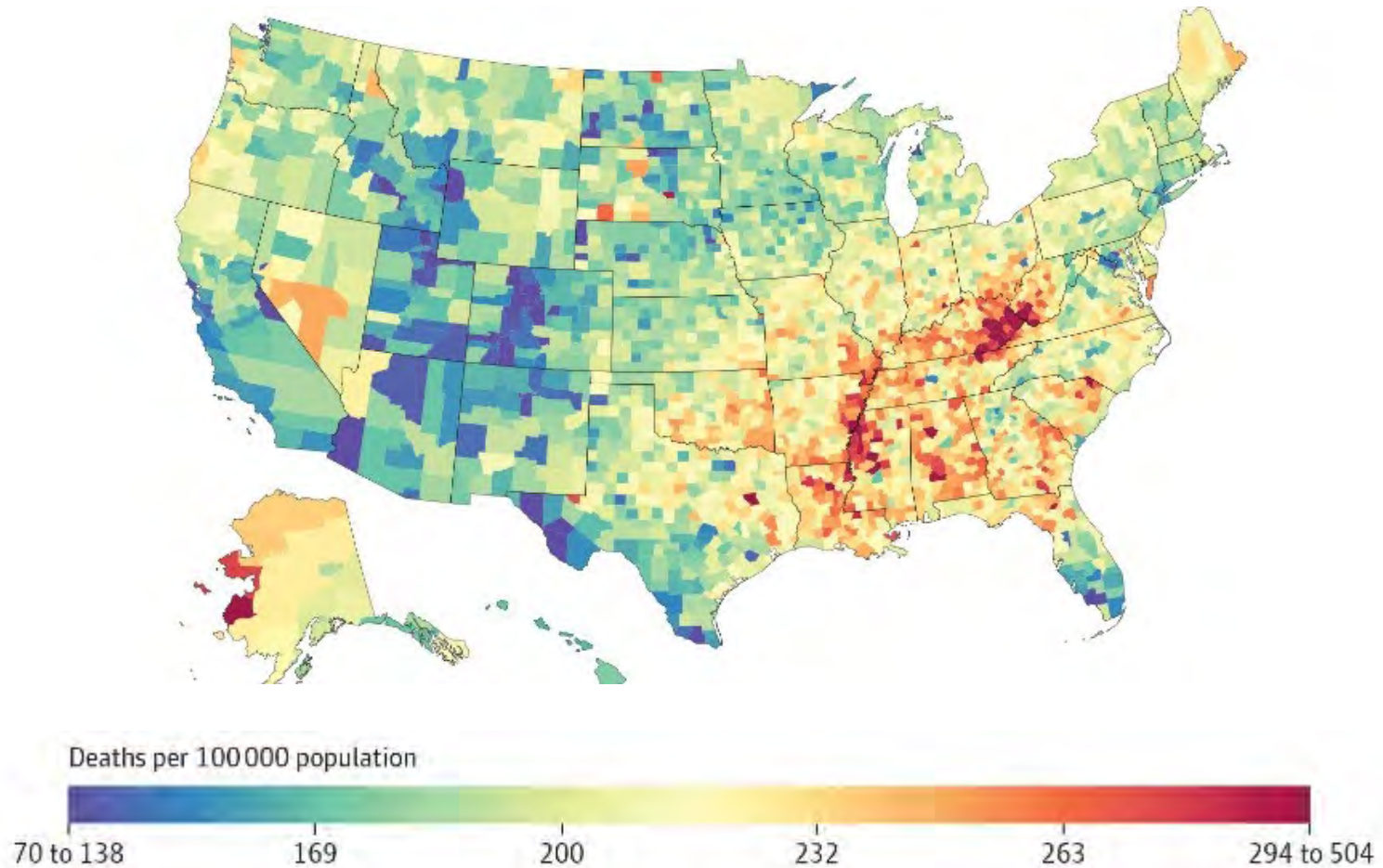
Poverty Rates (2011-2015)



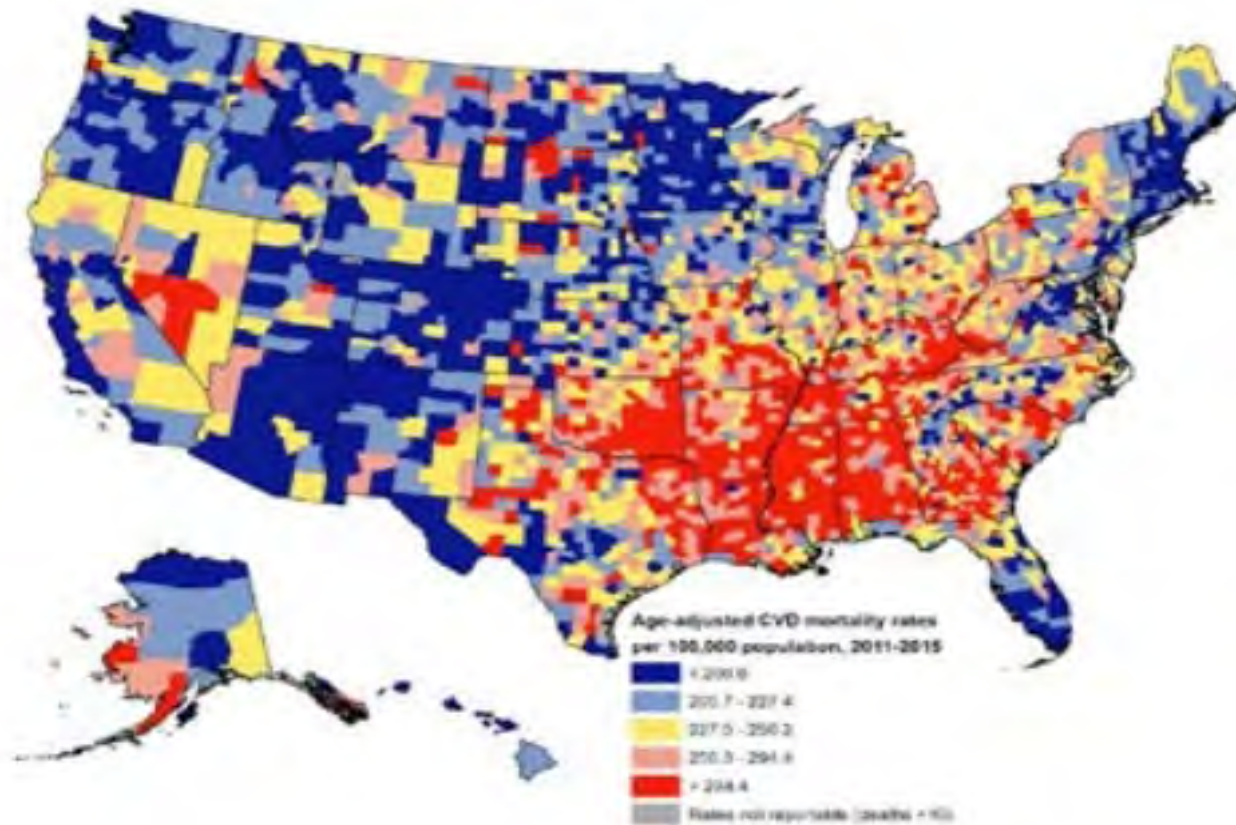
All cause mortality rates per 100,000 (2011-2015)



Cancer mortality rates per 100,000 2014



Cardiovascular disease mortality rates per 100,000 (2011-2015)



Who is trying to meet Alabama's health workforce needs?

- 4 medical schools (7 campuses)
- 8 Nurse Practitioner programs
- 2 Physician Assistant programs (soon to be a 3rd PA program)
- 1 Dental School
- 2 Pharmacy Schools
- 1 Optometry School
- Many other needed allied health training programs

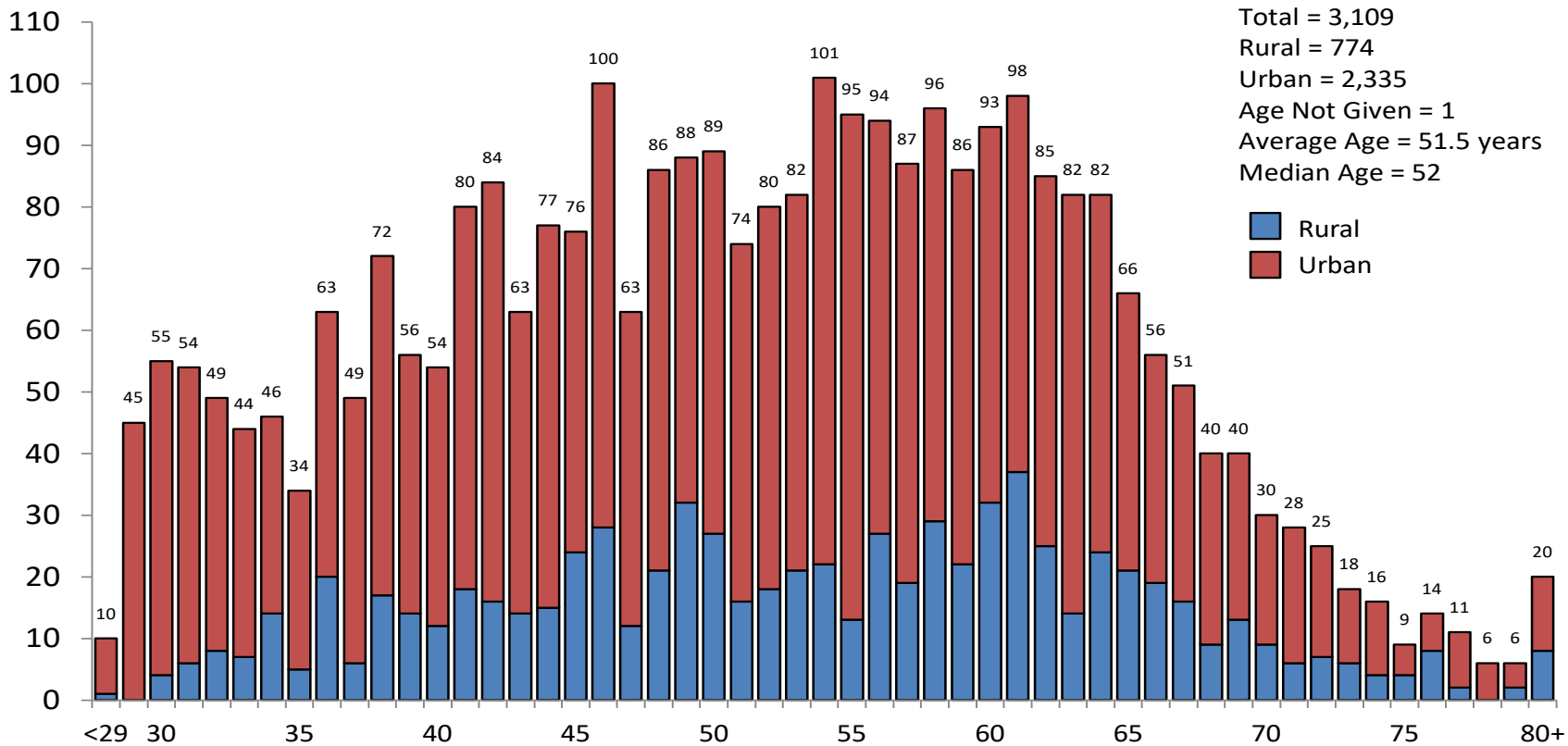
Opportunity exists for PPC in Alabama

- **3,713 (36%)** primary care physicians (45th in primary care physician to population ratio) – an aging population
- **4,260** NPs in collaborative practice in AL (most in primary care) – *5th fastest growing job in AL!*
- **727** physician assistants in AL (most not in primary care)

According to Hooker and Muchow (2015), Alabama has the lowest state ratio of NPs and PAs to population

(40 and 8 per 100,000, respectively)

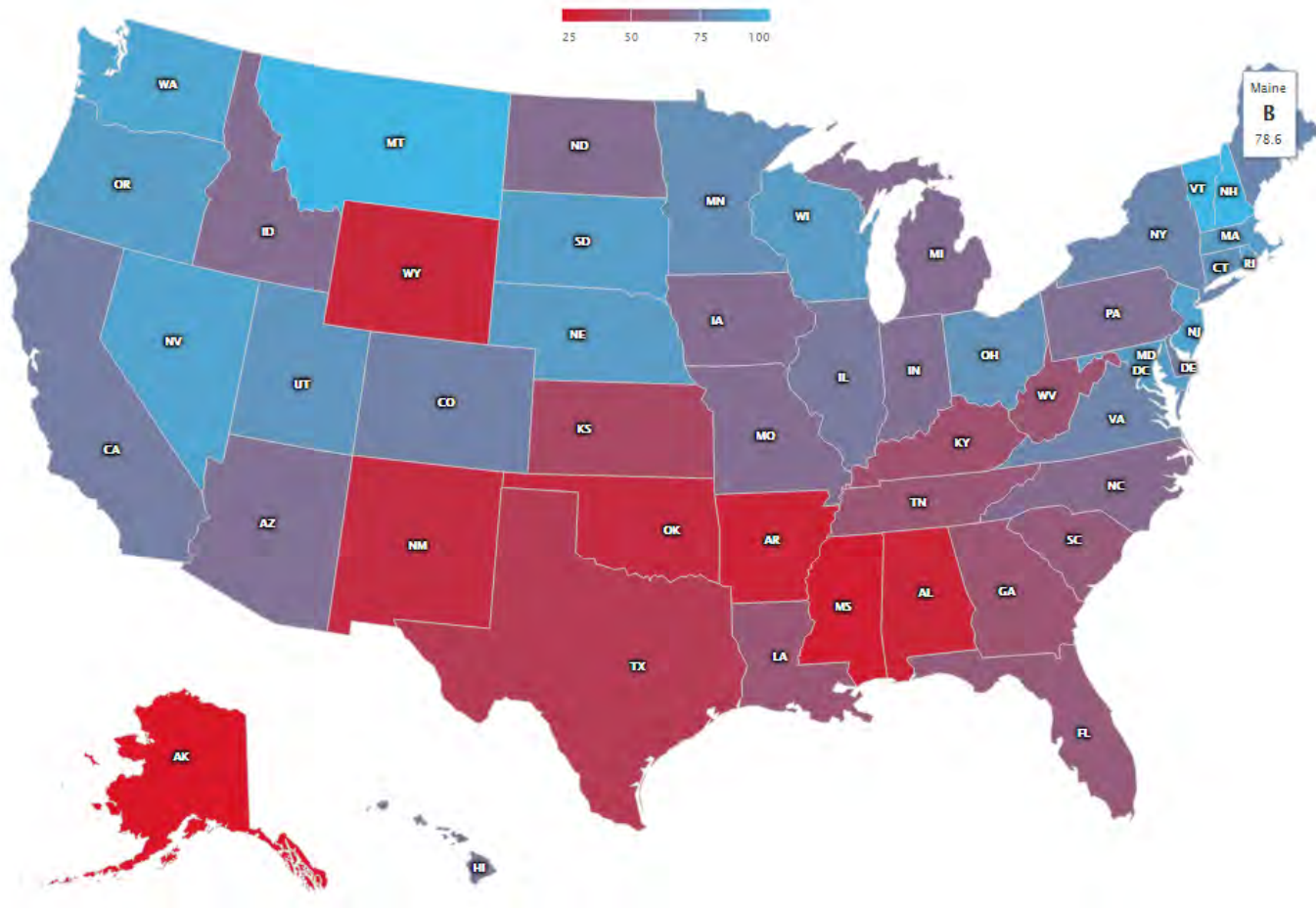
Primary Care Physicians Actively Practicing in Alabama's Rural and Urban Counties by Age, 2015



SOURCE: Alabama Medical Licensure Commission's 2015 Licensed Physician Data Base.

How does your state rate?

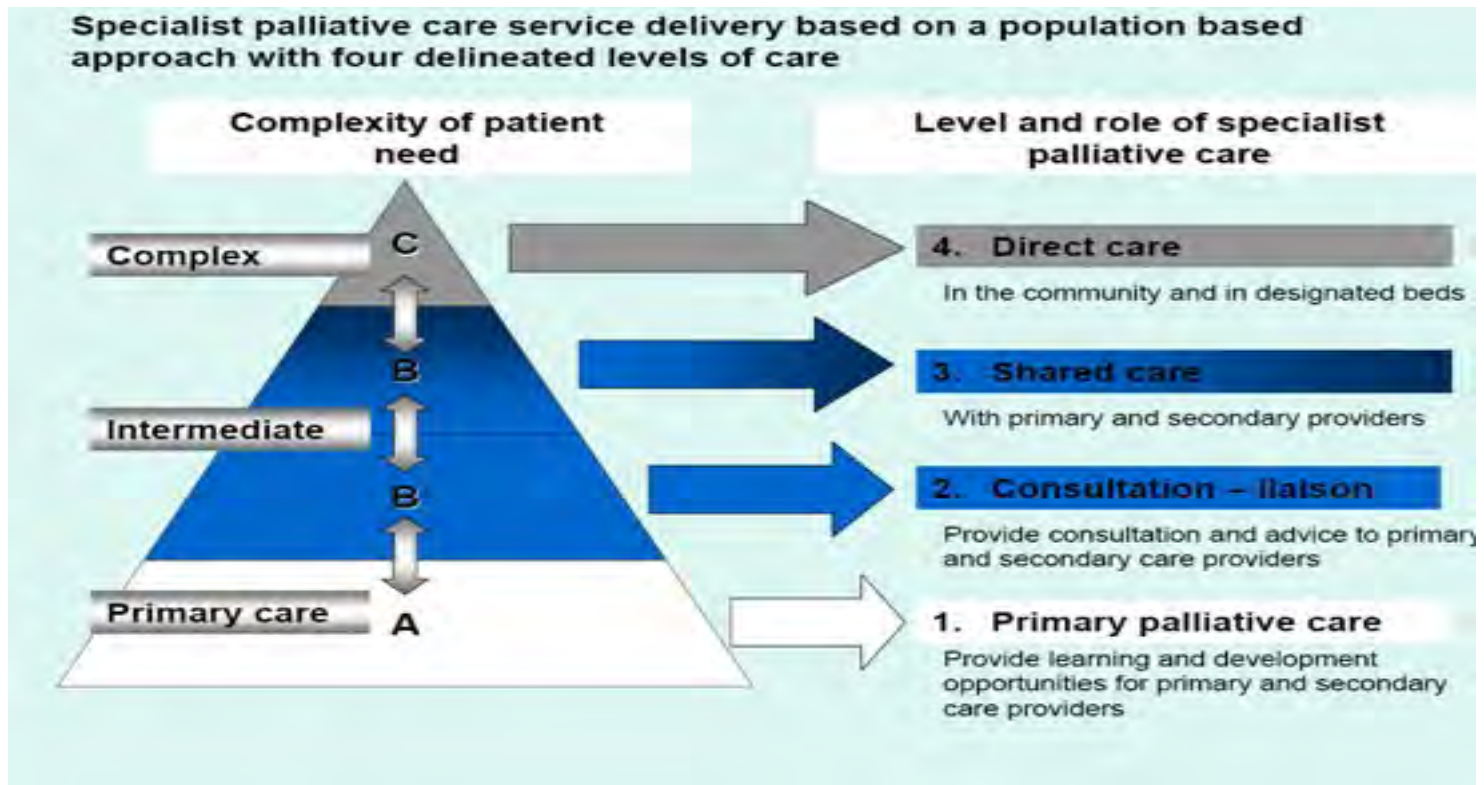
Hover over a state to view its grade



Highcharts.com © Natural Earth

<https://reportcard.capc.org/>

Resources for PPC Practitioners



Adapted from Palliative Care Australia. A guide to palliative care service development: A population based approach. Canberra: PC Australia, 2005. <http://palliativecare.org.au/wp-content/uploads/2015/05/A-guide-to-palliative-care-service-development-a-population-based-approach.pdf>

Adapted from Eagar K, Gordon R, Quinsey K, Fildes D. (2004). Palliative care in Tasmania: current situation and future directions. Wollongong: Centre for Health Services Development, Univ. of Wollongong.

<https://ro.uow.edu.au/cgi/viewcontent.cgi?referer=&httpsredir=1&article=1012&context=chsd>

Practice and Team Resources

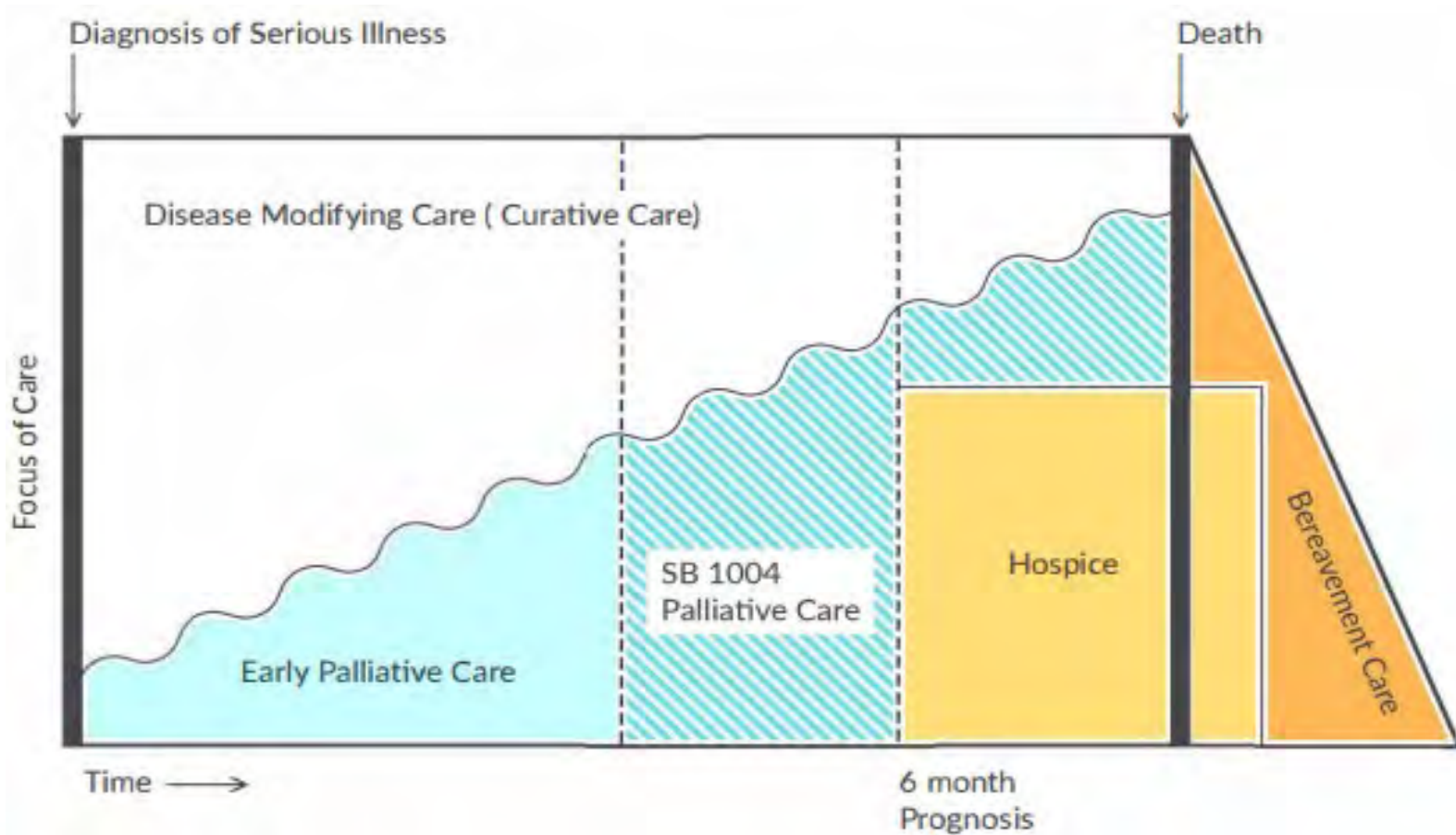
Palliative Care Leadership Centers Training Program (PCLC)

- <https://www.capc.org/palliative-care-leadership-centers/how-pclc-works/>
- <https://www.uab.edu/medicine/palliativecare/training/leadership>
- International Network for Cancer Treatment and Research (INCTR) <http://inctr-palliative-care-handbook.wikidot.com/INCTR>
[Palliative Care Handbook](#)
 - handbook on how to improve quality of palliative care in resource poor areas
- Toolkit for the development of palliative care in the community <http://journals.sagepub.com/doi/pdf/10.1177/0269216314545006>

Education/Training Resources

- Clinical Training Academy at UAB
<https://www.uab.edu/medicine/palliativecare/training/clinical>
- Center to Advance Palliative Care (CAPC) Training
<https://www.capc.org/providers/courses/>
- End of Life Nursing Education Consortium (ELNEC)
<https://www.relias.com/product/el nec-training>
- Education in Palliative and End-of-Life Care (EPEC)
<https://www.bioethics.northwestern.edu/programs/epec/>
- CAPC Mapping Project
<https://mapping.capc.org/>
- HeartCareCHF App

Successful Models of Care in PPC



California Department of Health Care Services. (2018). Care model for SB 1004 medi-call palliative care. Retrieved from <https://www.dhcs.ca.gov/provgovpart/Pages/Palliative-Care-and-SB-1004.aspx>

Community Model of Care: RPaSS (1)

Rural Palliative Supportive Service (RPaSS)

- Chronic life-limiting illness
- Biweekly in-home visits
- Nurse navigator and community-based clinical team
- Assessment and care coordination
- 17 month intervention
- Community-based approach



ORIGINAL RESEARCH

Feasibility of a rural palliative supportive service

B Pesut¹, BP Hooper¹, CA Robinson¹, JL Bottorff¹, R Sawatzky², M Dalhuisen¹

¹School of Nursing, University of British Columbia, Kelowna, British Columbia, Canada

²School of Nursing, Nisqually Science Centre, Tri-city Western University, Langley, British Columbia, Canada

Submitted: 22 April 2014; Revised: 16 September 2014; Accepted: 25 September 2014; Published: 4 May 2015

Pesut B, Hooper BP, Robinson CA, Bottorff JL, Sawatzky R, Dalhuisen M

Feasibility of a rural palliative supportive service

Rural and Remote Health 15: 3116. (Online) 2015

Available: <http://www.rrh.org.au>

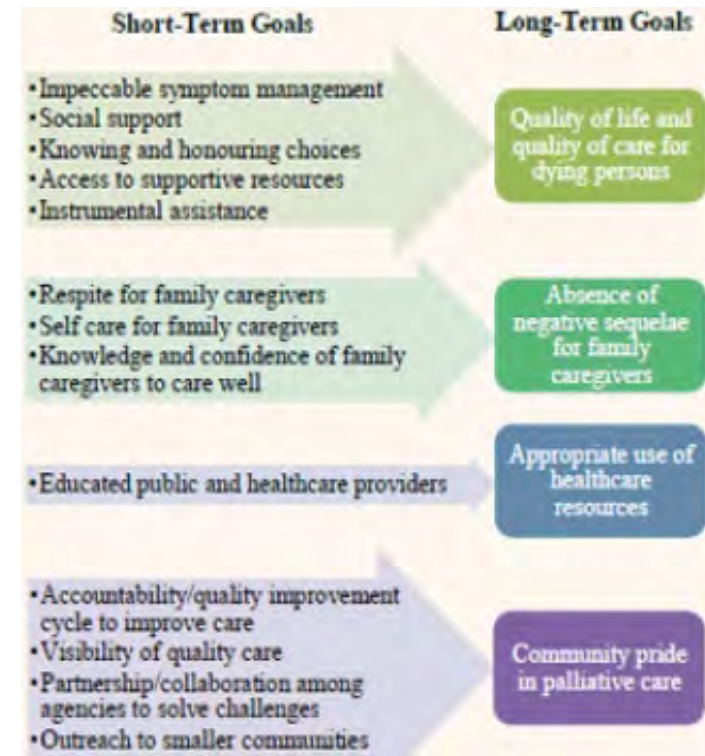
Pesut, B. et al (2015). Feasibility of rural palliative supportive service. *Rural and Remote Health*, 15(3116), 1-16.

Pesut, B. et al (2017). Nurse-led navigation to provide early palliative care in rural areas: A pilot study. *BMC Palliative Care*, 16(37), 1-10.

Community Model of Care: RPaSS (2)

Outcomes

- Acceptability of intervention
 - 393 in-person visits conducted
 - Only 19 visits declined (4%)
- Successes
 - Bridging gap between health and social issues
 - Community capacity-building
 - Relationship with nurse
 - Well-validated instruments
 - Addressed complex-multifaceted needs for the patient and caregiver



Pesut, B. et al (2015). Feasibility of rural palliative supportive service. *Rural and Remote Health*, 15(3116), 1-16.

Pesut, B. et al (2017). Nurse-led navigation to provide early palliative care in rural areas: A pilot study. *BMC Palliative Care*, 16(37), 1-10.

Telehealth Model of Care: ENABLE

ENABLE (Educate, Nurture, Advise,
Before Life Ends)

- Telehealth concurrent palliative care model
- Implementation in advanced cancer and heart failure
- Palliative care clinician
- Dyad study (patient and caregiver)
- Six structured telephone sessions
 - Charting Your Course: An Intervention for Patients with Advanced Cancer

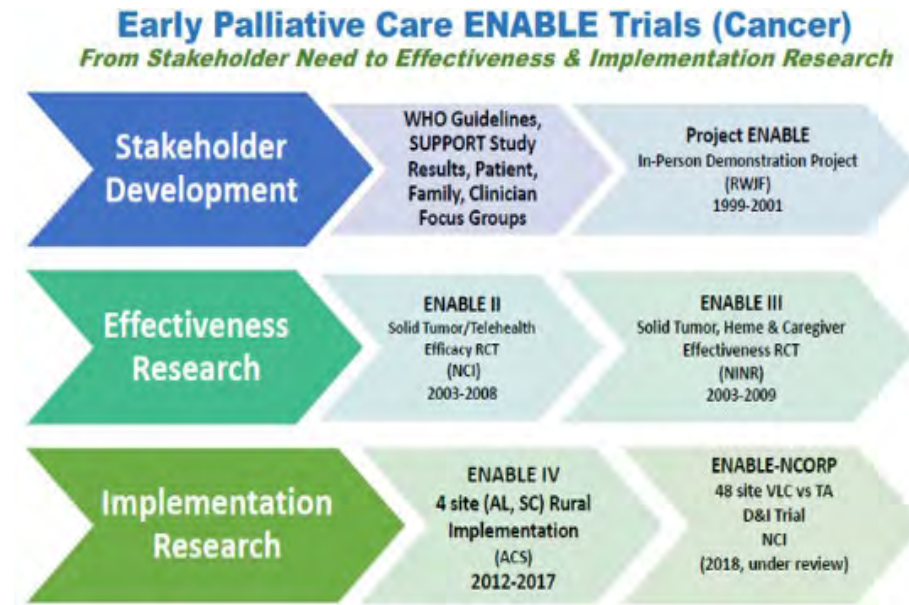


1. Bakitas, M. A. et al. (2015). Early versus delayed initiation of concurrent palliative e oncology care: Patient outcomes in the ENABLE III Randomized Controlled Trial. *J Clinical Oncology*, 33(13), 1438-1445.
2. Bakitas, M. A. et al. (2009). Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: The Project ENABLE II randomized controlled trial. *JAMA*, 302(7), 741-749.
3. Dionne-Odom, N. et al. (2015). Benefits of early versus delayed palliativecare to informal family caregivers of patients with advanced cancer: Outcomes from the ENABLE III randomized controlled trial. *J Clinical Oncology*, 33(13), 1446-1452.

Telehealth Model of Care: ENABLE

Outcomes

- **Patient**
 - Improved QOL
 - Decreased depression
 - Improved symptom burden
 - Improved survival
- **Caregiver**
 - Lower depression and stress burden



1. Bakitas, M. A. et al. (2015). Early versus delayed initiation of concurrent palliative e oncology care: Patient outcomes in the ENABLE III Randomized Controlled Trial. *J Clinical Oncology*, 33(13), 1438-1445.
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Hybrid Palliative Care

General Practitioners and Specialist Oncology Nurses

- **Oncology nurses:**
 - Postgraduate palliative care training
 - Offered recommendations related to disease management
- **General practitioner:**
 - Knowledge about patient and caregiver
 - Available community resources



Hybrid Palliative Care

Outcomes

- Assisting with interprofessional dialogue
- Specialized care for patient and caregivers
- Complimentary competencies

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BMC Health Services Research

RESEARCH ARTICLE

Open Access

Teamwork in primary palliative care: general practitioners' and specialised oncology nurses' complementary competencies

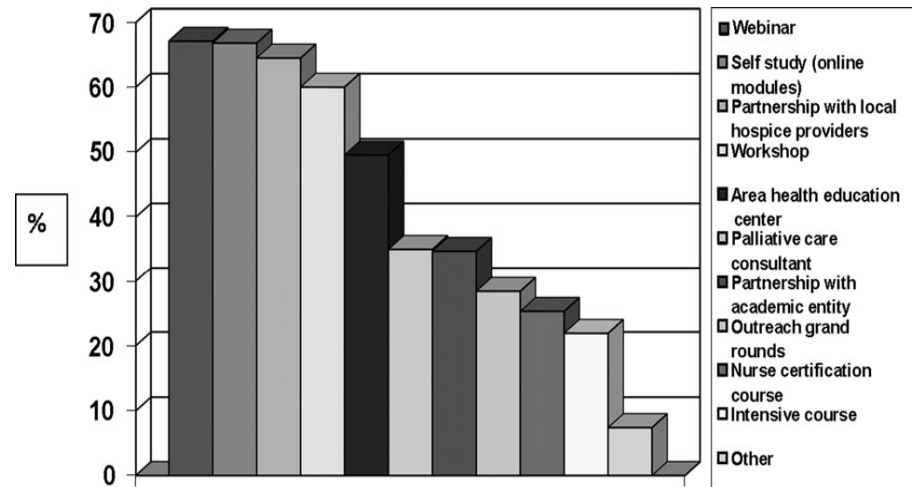


May-Lill Johansen^{1*}  and Bente Ervik^{2,3}

Palliative Care Education

Palliative Care Needs Assessment

- Awareness, activity, and available resources in rural hospital
 - Assess palliative care education
 - Lack of knowledge by providers
- Outcomes
 - Need staff to attend
 - Barriers: location, funding, electronic educational offerings, timing



Palliative Care Education

- APRN Palliative Care Externship
 - Experiential learning opportunity
 - Didactic education
 - Clinical and programmatic areas
- 5-day program
- Nationally recognized interdisciplinary palliative care team
- Outcomes (at 6 months)
 - 77.1% professional goals met
 - 88.6% personal goals met



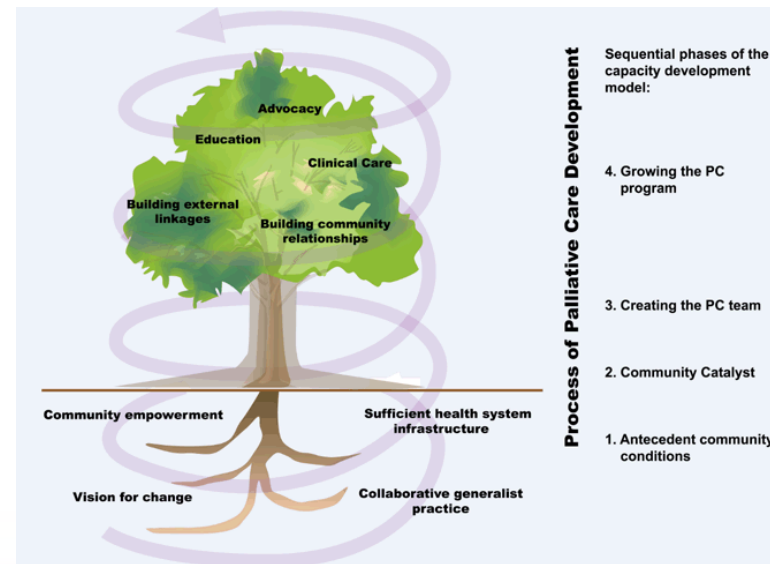
From utopia to reality...

Recommendations

- Educating and training primary care providers on PPC
- Development of external resources and support
- Ongoing networking
- Community-based metrics
- Reimbursement
- Redesigning care delivery
- Public health strategy for PPC

Next Steps

- Community assessments
- Identify facilitators and barriers



Kelley, M. L. et al. (2008). Developing rural palliative care: Validating a conceptual model. *Rural and Remote Health*, 11(1717).

