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

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Disclosures

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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. 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

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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

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<tr>
<td>Palliative care services</td>
<td>+ Palliative care approach everywhere</td>
<td>Palliative approach in all settings - with specialist palliative care services for complex cases</td>
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<td>Specialist services</td>
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<td>Institutional approach</td>
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<td>Services’ approach</td>
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“[...] 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.”

• 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
Figure 9: Factors required to achieve Universal Health Coverage

- **Addresses the determinants of health**
  - Undertakes actions related to determinants of health (e.g. education, living conditions, etc.)

- **Affordable**
  - A system that ensures that people do not suffer financial hardship when using health services.

- **Available**
  - Availability of essential medicines and technologies to diagnose and treat medical problems.

- **Competent workforce**
  - Sufficient capacity of well-trained motivated workforce to provide care to meet patients' needs based on best available evidence.

- **Effective and efficient health system**
  - Meets the health needs through people-centred integrated care across the entire continuum of care.

ICN. Nurses - A voice to lead: Health is a human right (2018)
https://2018.icnvoicetolead.com/resources/
Operationalizing PPC - global efforts (2)
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.

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.

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. 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.

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.

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.

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
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

So, is Primary Palliative Care a utopia or can it become a reality for rural Alabama?
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)

62 of 67 counties have primary care HPSA designations:
- 51 whole county
- 11 partial county
Alabama’s Mental Health & Dental Health HPSAs
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.
Alabama poverty and health

Poverty 2017

Health Outcomes 2017
Health literacy in rural Alabama
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

Total = 3,109
Rural = 774
Urban = 2,335
Age Not Given = 1
Average Age = 51.5 years
Median Age = 52

SOURCE: Alabama Medical Licensure Commission’s 2015 Licensed Physician Database.
Implementing PPC in rural Alabama
Resources for PPC Practitioners


Practice and Team Resources

Palliative Care Leadership Centers Training Program (PCLC)

- [https://www.capc.org/palliative-care-leadership-centers/how-pclc-works/](https://www.capc.org/palliative-care-leadership-centers/how-pclc-works/)
- [https://www.uab.edu/medicine/palliativecare/training/leadership](https://www.uab.edu/medicine/palliativecare/training/leadership)

**International Network for Cancer Treatment and Research (INCTR)**


- Handbook on how to improve quality of palliative care in resource poor areas

**Toolkit for the development of palliative care in the community**

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/elnec-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

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

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


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

Telehealth Model of Care: ENABLE

Outcomes

• **Patient**
  • Improved QOL
  • Decreased depression
  • Improved symptom burden
  • Improved survival

• **Caregiver**
  • Lower depression and stress burden

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

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
