HUMBOLDT STATE UNIVERSITY

Developing Capacity for Palliative Care in Rural Communities



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Global Social Welfare Digital Summit

February 2020

Learning Objectives

1. Demonstrate a foundation understanding of the challenges of providing palliative care in rural communities.

2. Understand the value of developing campus-community partnerships to build capacity.

3. Identify practical ways to empower people to die well in rural community.

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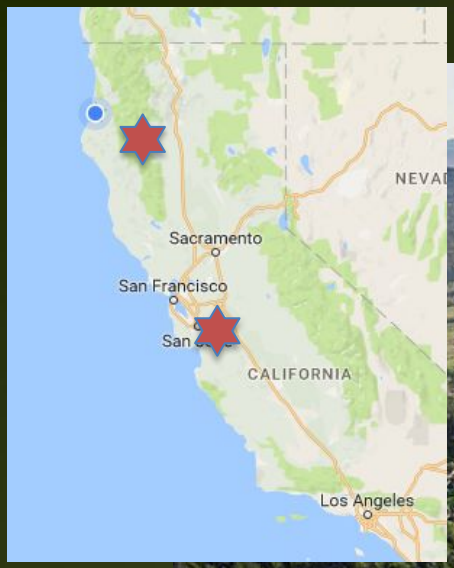


Considerations for Community Health

- Poverty impacting the social correlates of health
  - 60% of residents are housing insecure
  - 1 in 5 people in Humboldt County live at or below the poverty line
- Higher rates of of chronic illness
  - Often multiple chronic illnesses
  - Stroke rate 2x that of California
  - Smoking, Obesity, Diabetes
- Lack of access to nearby medical services, limited insurance plans, shortage of providers
  - 52.9% of people could not see a medical provider due to cost

Sources: National Center for Health Statistics. Health, United States, 2016: With Chartbook on Long-term Trends in Health. Hyattsville, MD. 2017. | Moy E

U.S. Causes of Death, age of 65+

1. Heart Disease
2. Cancer
3. Chronic Lower Respiratory Diseases
4. Cerebrovascular Disease
5. Alzheimer's Disease
6. Diabetes
7. Unintentional Injury
    - Falls make up 55% of unintentional injuries
    - MVA are second most common cause

Humboldt County Mortality, 2014-2016

Ages 45-64 (1,549 deaths)

1. Cancer (217)
2. Cardiovascular Disease (180)
3. Drug Related Deaths (112)

- Followed by Liver Disease & Suicide

Ages 65+ (4,445 deaths)

1. Cardiovascular Disease (1,079)
2. Cancer (1,079)
3. Stroke (494)

Review of the Literature

Review Selection Criteria:

1. Community capacity development
2. Rural health services
3. Rural palliative care services

Studies (n=79) were grouped by subject matter into one of three categories:

1. Patient and caregiver perspectives
2. Professional attitudes, knowledge and practice issues
3. Health care services

The Problem Identified

- Most people (80- 87%) prefer to die at home
- 4/5 did not change their mind as illness progressed
- 60% die in acute care facilities
- 20% die in nursing homes
- 20% die at home

Video: "Ain't The Way to Die", ZDOGG, MD

Gomes, B., Calanzani, N., Gysels, M. *et al.* Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliat Care* **12,** 7 (2013). https://doi.org/10.1186/1472-684X-12-7Gomes, B., Calanzani, N., Gysels, M. *et al.* Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliat Care* **12,** 7 (2013). https://doi.org/10.1186/1472-684X-12-7

FACTORS INCREASING LIKELIHOOD OF DEATH AT HOME

- Multidisciplinary palliative care available in the home
- Early referral to palliative care
- The type of disease
- Few or no hospitalizations in end-of-life period
- Not living alone
- Preference of patient & family
- An informal caregiver with strong coping systems

Building Capacity

- **January 17, 2019** -the U.S. House of Representatives re-introduced H.R. 647
- **April 2019-** Shiley Institute for Palliative Care- Call for campus partners
- **May 2019-** Partnership formed between Humboldt State University and Resolution Care Network
- **July 10, 2019-** the U.S. Senate re-introduced S. 2080, the Palliative Care and Hospice Education and Training Act (PCHETA).
- **November 4, 2019-** Est. The Full Life Institute at Humboldt State University & applied for Campus Partner Status.

The Full Life Institute

The mission of the Institute is to improve access to a full life throughout an individual's lifespan, promoting, conducting, and disseminating research that includes the end of life.

We do this by supporting education and analysis on issues related physical, mental, and transpersonal dimensions of death and dying, serious chronic illness, terminal diagnoses, aging, and suicide, with special attention to rural context, low income and other vulnerable populations -- and using research to advance tools for transformational helping that expand awareness, expertise, and radical compassion.

Our Partner

Palliative Care Team

ResolutionCare is a Professional Corporation formed by Michael D. Fratkin, M.D. in fall of 2014.

Started through crowdsourcing efforts in response to the unmet needs of the community.

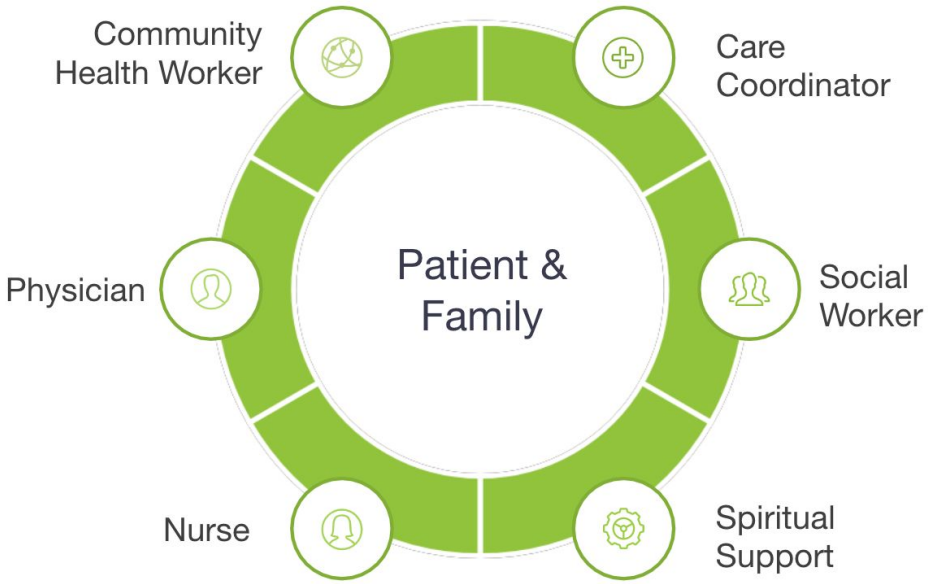
Hospice versus Palliative Care

- Hospice provides care to people experiencing terminal illness. It is based on the belief that everyone has the right to die pain-free and with dignity.

- Palliative care, also called comfort care, supportive care, serious illness care, or symptom management, provides treatment of symptoms or suffering at any stage of a serious illness.

- Both hospice and palliative care services can improve the quality of life for rural residents of all ages who are dealing with serious illness or injury.

Palliative Care Model



Value Based

Move from fee-per-service to capitated payments enables full spectrum team care and efficient resource leverage

Community

Interdisciplinary care delivered to the home, directly involving patient, family and caregivers.

Technology

Telehealth technology enables a networked demand-supply model, with geographic reach and layered services

Current State of Access

Today, in California alone, more than 500,000 people are clinically eligible for palliative care.

Less than 1% of them have access to it.

What challenges are faced by rural hospice and palliative care providers?

- Financial issues, such as reimbursement and operating costs
- Rural factors, including population change, economics, culture, and geography
- Federal regulations and policies, such as the requirement for face-to-face visits for recertification of hospice patients

What challenges are faced by rural hospice and palliative care providers?

- Workforce issues, including challenges in recruiting and retaining staff, and staff burnout
- Relationships with other health providers, and competition for resources and patients
- Technology issues, including limited access to broadband and connectivity problems

What challenges are faced by the rural hospice and palliative care workforce?

- Coping with fear and anger among patients and families who are having difficulty accepting the patient's illness or injury
- Dual Relationships- Emotional stress of caring for dying patients with whom they have close relationships
- Safety concerns related to traveling to remote areas with poor roads and communication infrastructure
- Lack of training programs geared specifically toward medical professionals who wish to specialize in hospice and palliative care
- Low retention rate among rural medical staff

What challenges are faced by the rural hospice and palliative care workforce?

- Salaries that may be lower than those earned by medical professionals in other specialty areas
- Work in some cases may be only part-time
- Skill set for a variety of complex chronic conditions may be required
- Scheduling such that hospice and palliative care providers may routinely work alone and without support
- Fewer medications and less medical equipment available in rural pharmacies

Challenges to Establishing Campus Community Partnerships

- Scarcity of resources in community funding
- Fear of competition
- Lack of understanding about university role in community
- Academics don’t necessarily understand current frontline provider issues
- Limitations of the academic year schedule

Benefits to Establishing Campus Community Partnerships

- Access to different sources of funding and grants & grant support that are meant for research and planning
- Students who can help engage work and research to build capacity
- Resources and relationships to provide technical assistance (i.e. technology, Tribal Community)
- Engage across sectors & providers

What we are doing

Working toward designation as CSU Palliative Care Campus Partner.

Developed a curriculum to help people talk about planning to die.

Applying for grants to address identified community needs.

Next Steps for the Full Life Institute

1. Increasing education
   a. Normalizing the discussion of death & death planning
   b. Listening to community needs
   c. Build partnerships with other organizations to learn about resources, opportunities and challenges
   d. Educating caregivers/ increasing support & resources
   e. Engage students to address workforce shortages
2. Increasing access
   a. Telemedicine
   b. Virtual Support Groups for Caregivers

Questions?

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