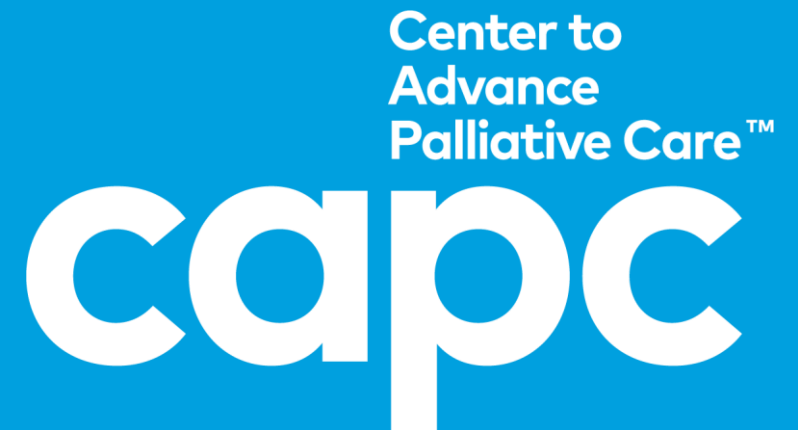


Bringing Palliative Care to Your Patients

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Advisory Council**

Marilee Malcolm – Nebraska Hospice and Palliative Care Association

Stacie Sinclair – Center to Advance Palliative Care



Disclosures

The presenters have nothing to disclose.

Objectives

Participants will be able to:

- Describe what palliative care is and how it ensures value in health care
- Discuss key considerations for rural health care providers in expanding palliative care access
- Locate additional resources on how to get started

Serious Illness Nationally and in Nebraska

- Nationally, 15-20% of the US population:
 - Geographic isolation
 - Lower socioeconomic status
 - Older age
 - Lower rates of insurance coverage
- Less than 8% of total MDs practice in rural areas, and there is limited specialty care which requires travel to access
- Approximately 9% of Nebraskans 18+ classified as “high need”
- Growing aging, sicker population in rural communities
- Pandemic has pushed out preventive care and testing - so will probably see higher rates of terminal illness in 5-10 years

No One is Taking Ownership

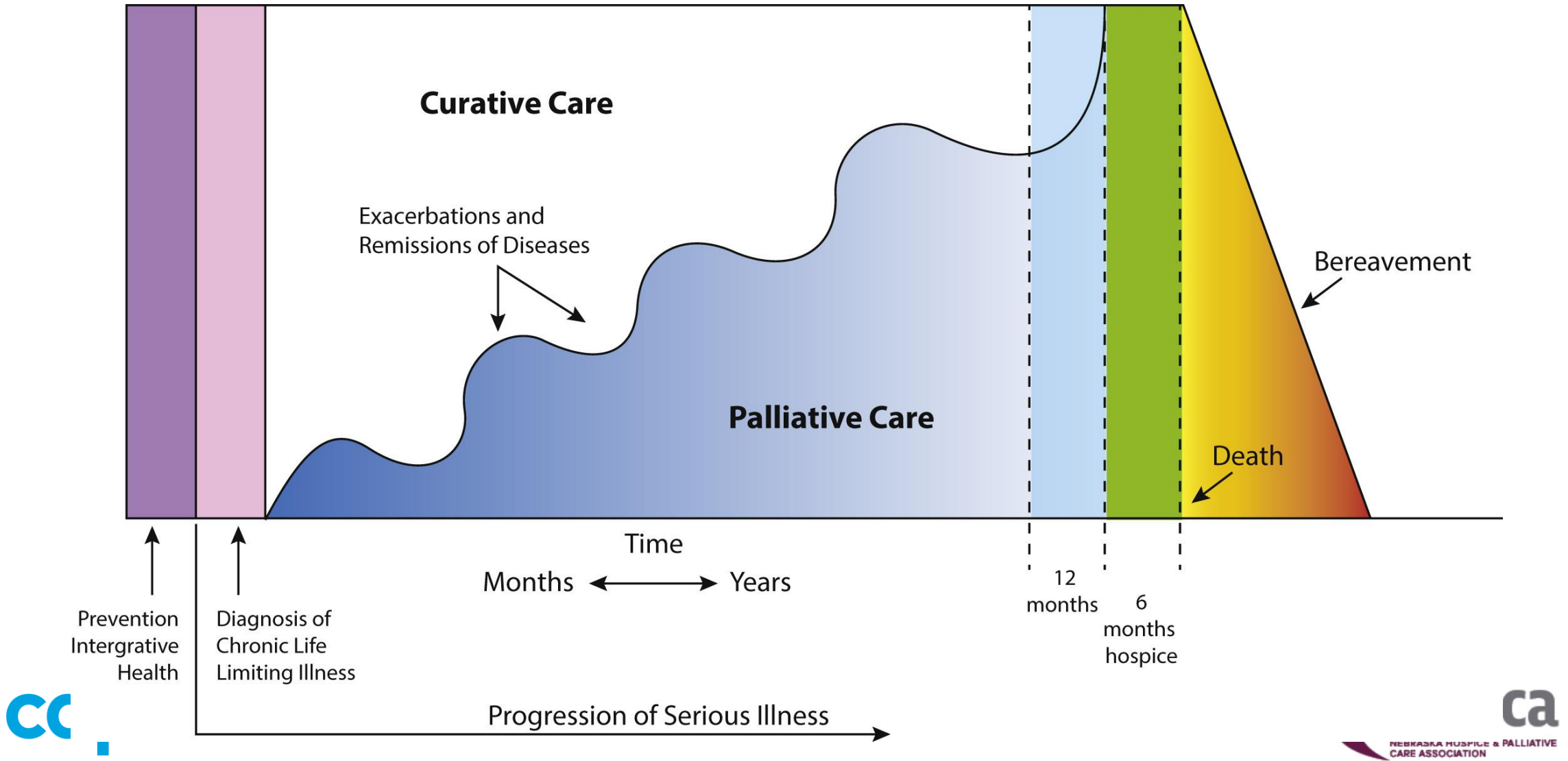
What is Palliative Care?

Palliative care is:

- Specialized medical care for individuals living with a serious illness.
- Focuses on providing relief from the symptoms and stress of a serious illness.
- Appropriate at any age in a serious illness, can be provided along with curative treatment.
- Based on the needs of the patient, not the prognosis.
- Goal is to improve the quality of life for both the patient and family.

Palliative Care Model

Source: Roth AR, Canedo AR (2019)



Palliative Care is a Bridge



Primary vs. Specialty Palliative Care

Primary palliative care is:

- provided by the primary care provider, and
- includes early identification and assessment of pain and other symptoms,
- as well as patient goals of care,
- within the skill set of all clinicians who care for seriously ill patients.

Specialty Palliative Care

Patients who have multiple morbidities, intractable symptoms, multiple ED/hospital visits, highly fragmented care, complex family dynamics, and overburdened caregivers often require palliative care specialists. Working with the primary care practitioner, these specialists:

- Devote time to patient/family counseling and meetings
- Are experts in the management of complex physical and emotional symptoms
- Coordinate and communicate care plans to all providers and across all settings.

Marcia's Palliative Care Story

- Diagnosed with stage 2C colon cancer in June of 2012, and then with stage III parotid gland cancer in November 2020.
- treatment regimens included surgery, chemotherapy and 30 radiation treatments - the last of which occurred during the height of the COVID 19 epidemic in Nebraska.
- As a career long hospice and palliative care certified RN, a bereaved family member whose brother died from an excruciating battle with cancer in 2014, and a survivor myself, I feel very strongly there must be greater access to palliative care in Nebraska.
- In addition to dealing with the management of complex physical symptoms, palliative care can transform the experience by attending to the complete needs of the patient and family.

Palliative Care is Vital in Rural Communities

- Palliative care principles and practices can support seriously ill patients, their families, and caregivers across settings of care
- Focuses on relieving suffering and improving quality of life - helping understand treatment options and facilitate effective communication
- Delivery models for rural community-based palliative care lags, even though rural populations are disproportionately ill, disabled, poor, and older. Also more likely to have a range of chronic conditions
- Palliative care programs and services align well with other efforts to redesign care delivery - increased coordination across care settings, focus on people with multiple chronic conditions

Palliative Care Requires a Shift in Mentality

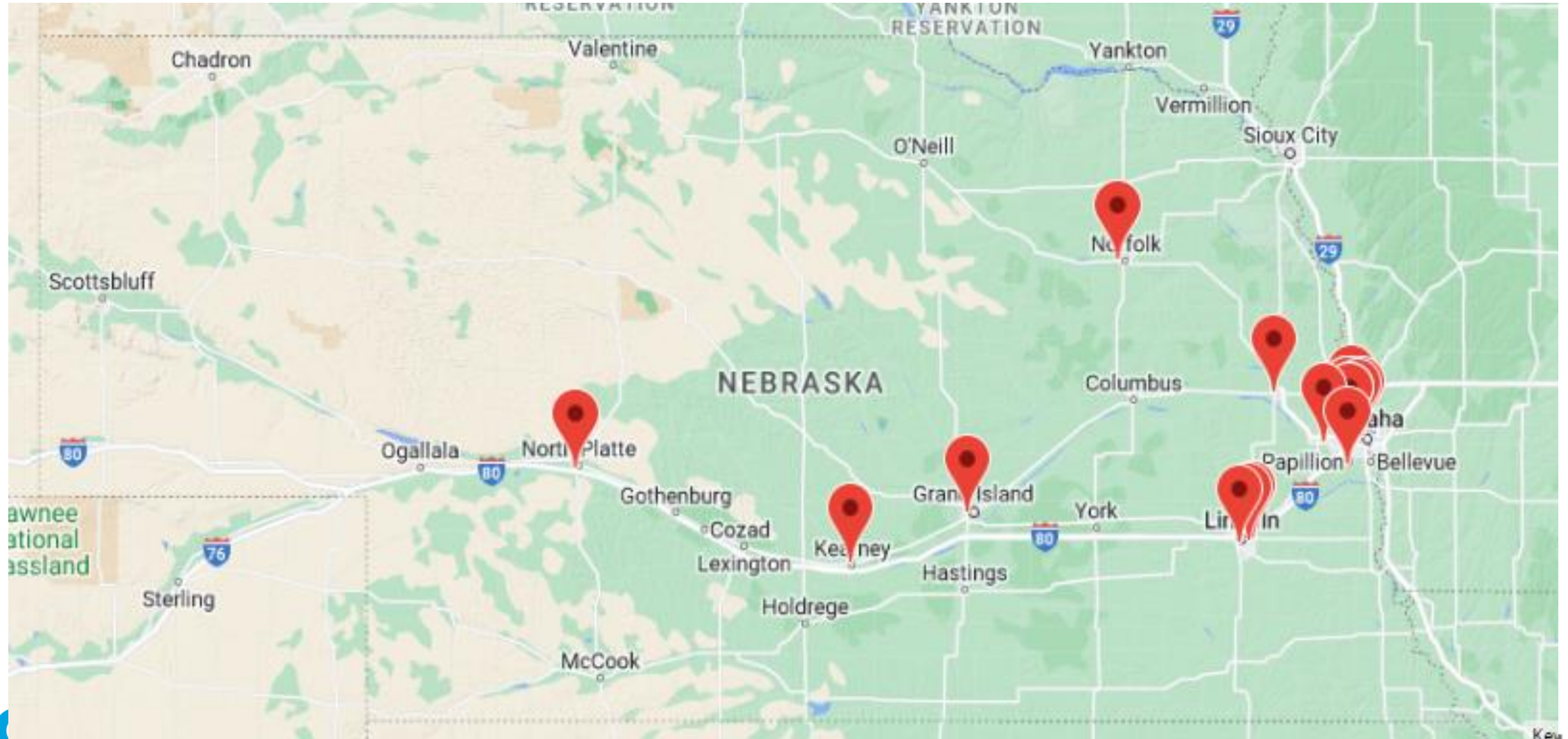
- Practitioners get into a “help help help” mentality - and patients never hear that symptom management is an option
- It can be easy to miss the window when palliative care would be beneficial
- In a rural setting, those long-term relationships with friends, neighbors, church members, etc. can complicate difficult discussions



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**‘I Don’t Want Jenny To
Think I’m Abandoning
Her’: Views On
Overtreatment**

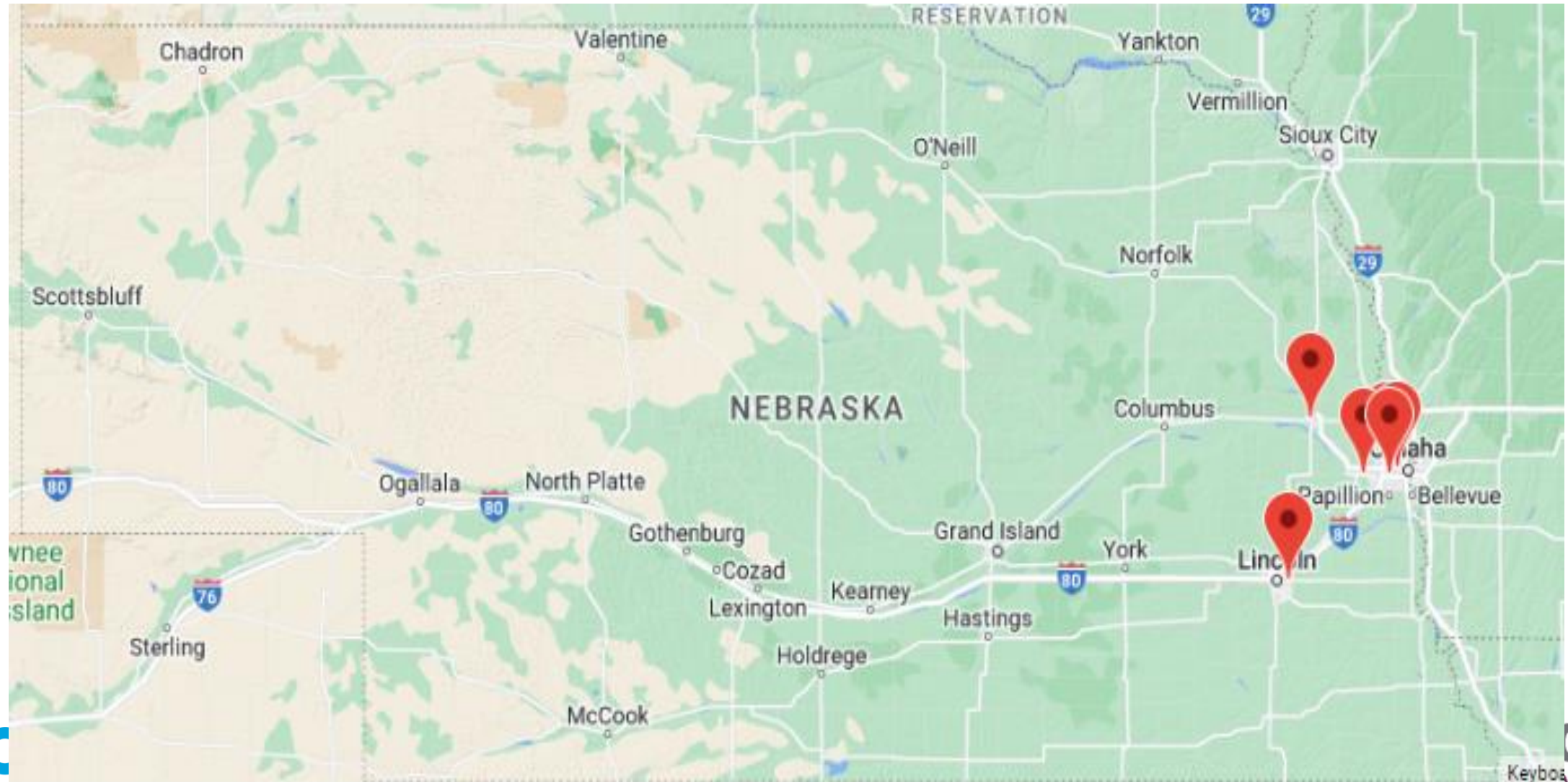
Current Specialty Palliative Care Landscape - Hospital



Nursing Home

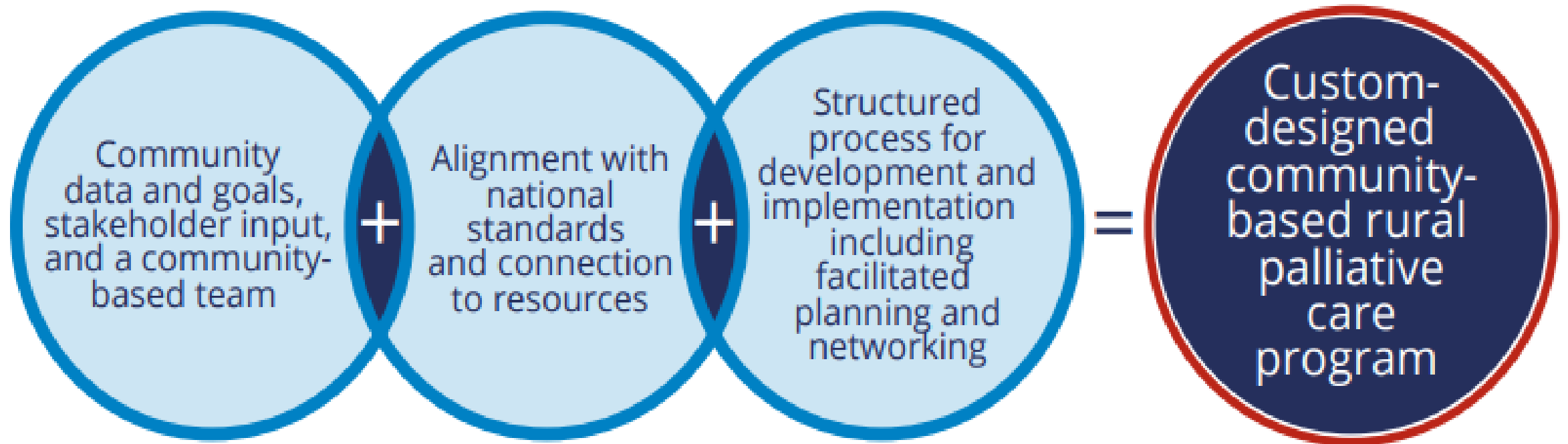


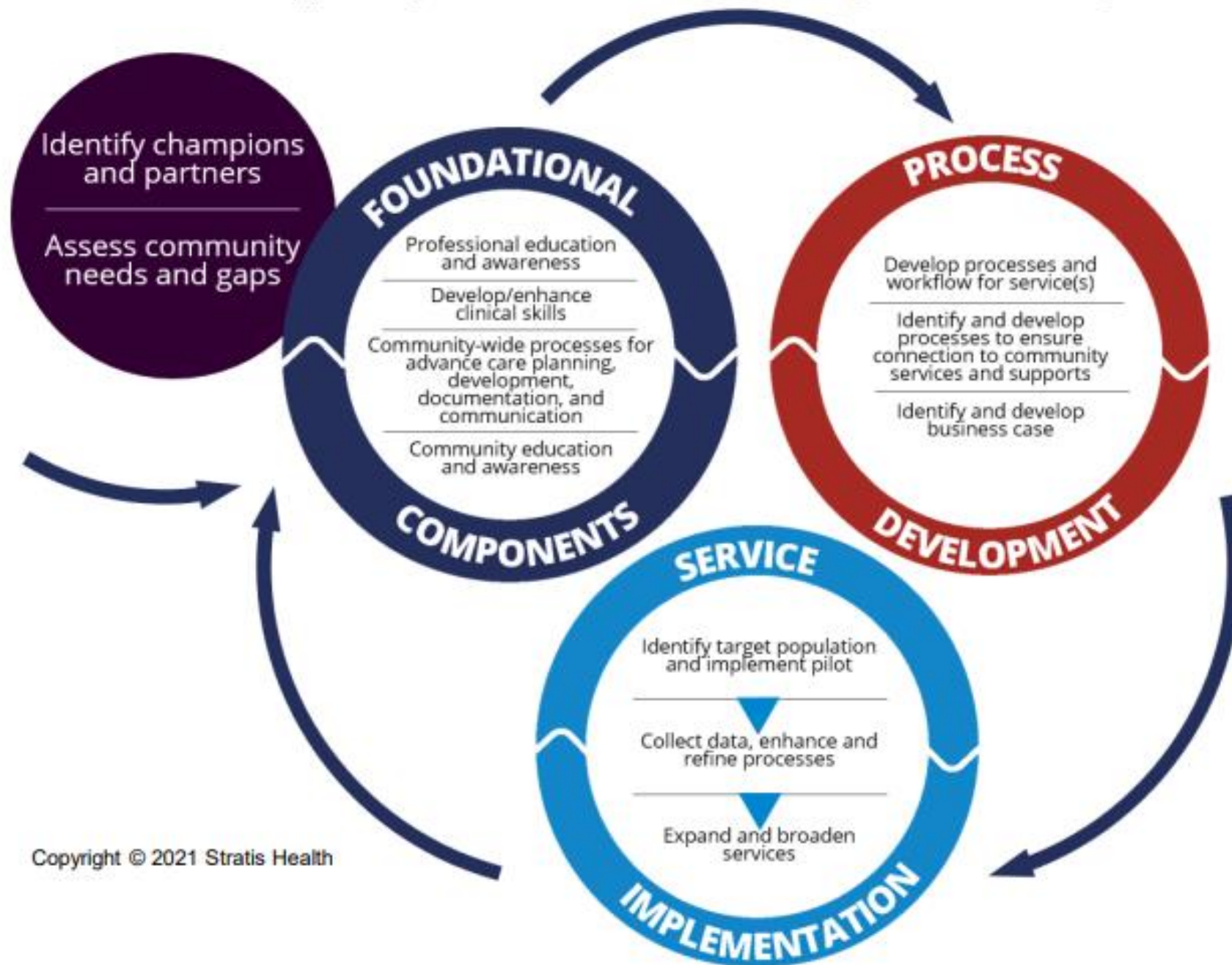
Office/Clinic



Opportunities for Rural Health Care Providers

Stratis Health Formula for Program Development





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Telehealth is a Key Operational Consideration

- Telehealth can improve access and equity, especially in rural, underserved populations
- Can encompass assessments, training, check-ins, remote monitoring, etc.
- Providers can deliver telehealth services across state lines, depending on rules set by state and federal policies. Interstate compacts simplify cross-state telehealth for specialists in participating states.
 - [Telehealth.hhs.gov/providers](https://telehealth.hhs.gov/providers) - compacts for the different professional types.
- Resources:
 - CAPC - [Telehealth and Palliative Care](#)
 - NHPCO - [Best Practices for Using Telehealth in Palliative Care](#)

Internal Capacity Building

- Rural health care providers and programs ALREADY have the building blocks for necessary skills - don't always need a specialist
- Areas to seek additional training:
 - Conducting a [comprehensive assessment](#) - physical, functional, cognitive, social, emotional, spiritual, cultural, financial, and caregiving aspects of care
 - [Pain](#) and [symptom management](#)
 - [Communication](#)
- Operational building blocks
 - [Stratis Health Rural Community-based Palliative Care Resource Center](#)
 - Center to Advance Palliative Care
 - [Identifying patients](#)
 - [Building the program\(s\)](#)
 - [Telehealth](#)
 - Etc.

Rural Community-based Palliative Care

Variables in Rural Palliative Care Program Structure

Methods of service delivery	Interdisciplinary team	Patient focus	Coordinating staff
Home visits	<p>All teams included physician, social work, nursing</p> <p>Other disciplines vary:</p> <ul style="list-style-type: none">• Rehabilitation services• Volunteers• Nurse practitioner• Chaplain• Pharmacy• Advance practice nurse in psychiatry	Hospice eligible but refused	Nurse practitioner
Clinic appointments		Infusion therapy	Registered nurse
Nursing home visits		Home care with complex illness	Social worker
Inpatient consultation		Inpatient consult when requested	Certified nurse specialist
Telephonic case management		Physician referred with complex illness	Advance practice nurse
Volunteer support visits/services		Nursing home residents – triggered by minimal data set (MDS) criteria	

Rural Palliative Care: Community Team Development

BUILDING

EVOLVING

THRIVING

Palliative Care Leadership

- Small group of inspired individuals
- Spreads knowledge
- Assesses needs and gains support
- Removes barriers

- Benefit of palliative care services is shared with patients, families, and providers
- Understands and supports palliative care development

- Provides motivation and resources for further palliative care development
- Empowers staff to build strong processes and consistent services

Advance Care Planning Processes

- A variety of processes and formats among providers and settings
- Sharing across settings is limited

- Alignment of processes and formats among providers and settings
- Plan in place for sharing across settings of care

- Aligned process, format, and communication channels across settings and the community
- Patient wishes are documented, accessible, and followed

Clinical Team – Palliative Care Skills, Interdisciplinary Team

- Palliative care skills are limited outside of hospice providers
- Interdisciplinary team (IDT) discussions are inconsistent and/or limited

- Increased awareness and palliative care skill building across broader sections of the health care workforce
- IDT discussions are more regular and structured

- Skills and knowledge are fully integrated across the team
- Formal and regular IDT meetings
- Linkages are strong for additional expertise and support as needed

Care Coordination, Collaboration with Community Services and Supports

- Limited; may be highly dependent on individual awareness of resources and/or patient engagement

- Services and access points are understood and available
- Identification of needs and gaps completed at a community level; care plans shared intermittently

- Referral and service processes are integrated across settings
- Care plans accessible, utilized, and dynamic; service development expands for identified gaps

Community Awareness of Palliative Care

- Limited and may be highly dependent on individual providers, patients, and families

- Common language about palliative care utilized among community partners
- Palliative care services are visible and becoming understood in the community

- Community understands, supports, and requests palliative care services and resources

Connecting to Specialty Palliative Care

Nebraska Providers and Services

Link

Bryan Palliative Care [↗](#)

CHI Health [↗](#)

Faith Regional Health Services [↗](#)

Mary Lanning Healthcare [↗](#)

Nebraska Cancer Specialists [↗](#)

Methodist Health System [↗](#)

UNMC Nebraska Medicine [↗](#)

Children's Hospital and Medical Center [↗](#)

Regional West [↗](#)

UNMC Department of Pediatrics [↗](#)

Palliative Care Service Directory [↗](#)

Southeast Nebraska Cancer Center [↗](#)



Resources

- Stratis Health Rural Palliative Care Tool Kit:
<https://stratishealth.org/toolkit/palliative-care-resource-center/>
- Nebraska Hospice and Palliative Care Association:
<https://www.nehospice.org/>
- Center to Advance Palliative Care: <https://www.capc.org/>
- National Hospice and Palliative Care Organization:
<https://www.nhpco.org/>
- GetPalliativeCare.org: <https://getpalliativecare.org/>
- Nebraska Palliative Care and Quality of Life Advisory Council:
<https://dhhs.ne.gov/Pages/Palliative-Care.aspx>

Questions?



**Thank
You!**





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