Palliative Care:

Helping Survivors and Caregivers

Kathryn Morsea, MD, HMDC

Goals

- Define palliative care
- Describe the palliative care program at Gallup Indian Medical Center
- Explain when and how patients and family get involved
- Discuss how palliative care consults get involved and why
- Describe how common symptoms such as pain and fatigue are managed

Nothing to disclose

The Nature of Suffering

"The relief of suffering and the cure of disease must be seen as twin obligations of a medical profession that is truly dedicated to the care of the sick. Failure to understand the nature of suffering can result in medical intervention that (though technically adequate) not only fails to relieve suffering but becomes a source of suffering itself."

-Eric J Cassell

Palliative Care Definition

- Palliative care is specialized health care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of a serious illness. The goal is to improve the quality of life for both the patient and the family.

- Palliative care is provided by a team of doctors, nurses, and other specialists who work with a patient's other doctors to provide an extra layer of support. Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment.

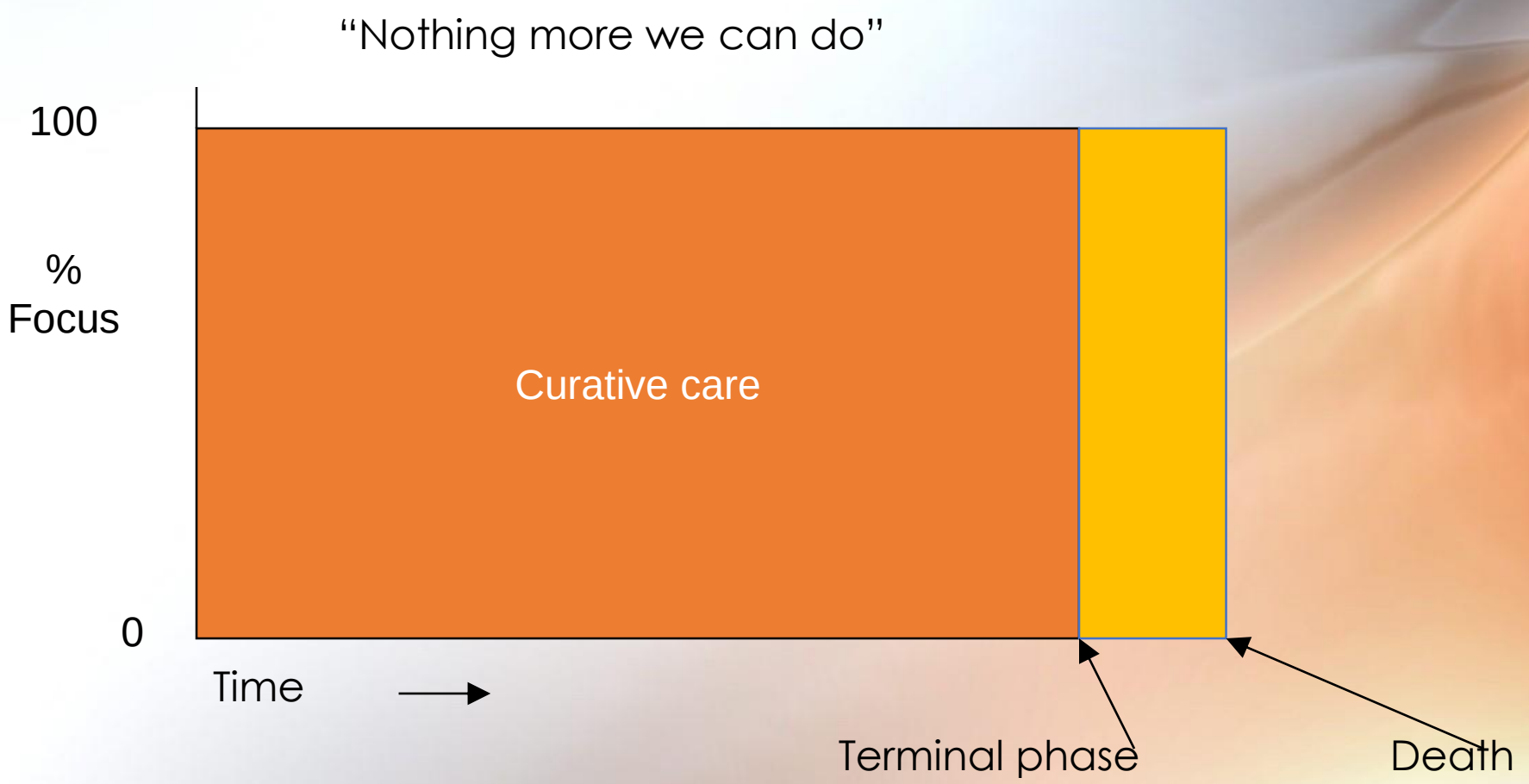
-Center to Advance Palliative Care

Palliative Care Definition

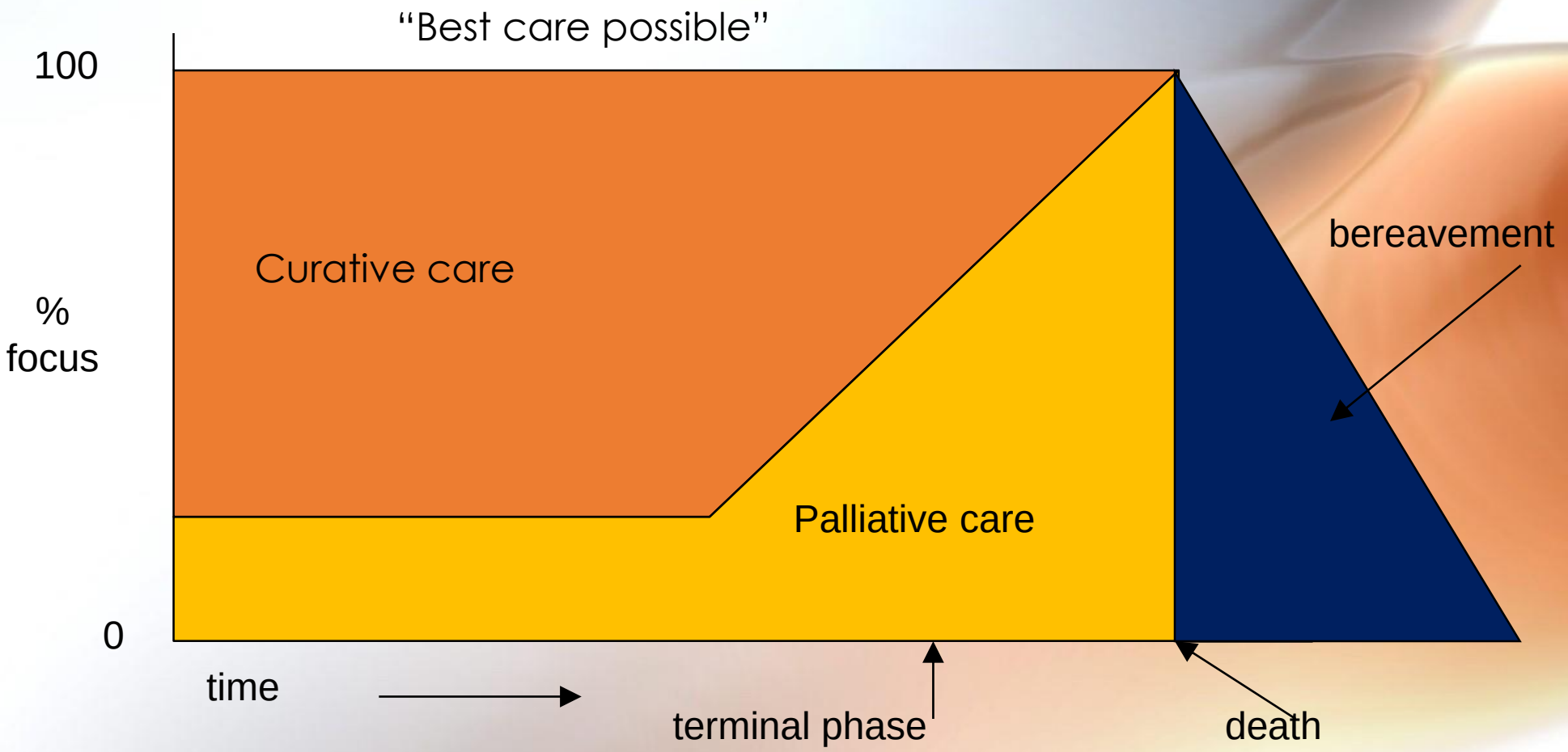
The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. Palliative care is both a philosophy of care and an organized, highly structured system for delivering care.

-National Consensus Project

"Old Model"


"Nothing more we can do"
100
% Focus
0
Curative care
Time
Terminal phase
Death

"New model"


"Best care possible"
100
%
focus
0
Curative care
Palliative care
bereavement
time
terminal phase
death

Benefits of Palliative Care

- Improves quality of life in patients with serious illness as well as caregivers.

  Dionne-Odom et al

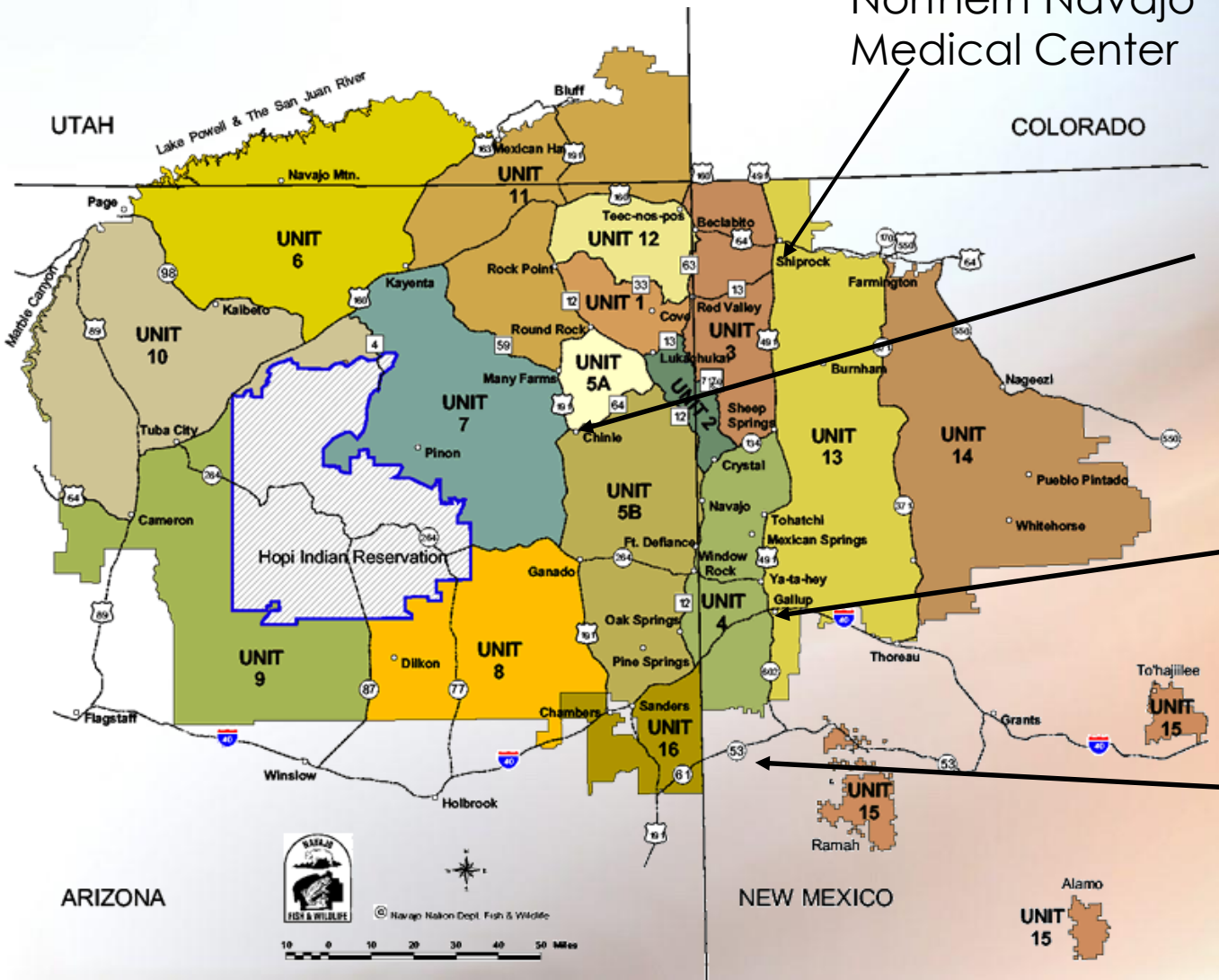
- There is evidence that suggests patients may live longer.

  Temel et al

- Decreases utilization of health care resources and cost of care.

  Morrison et al

Palliative Care Programs in Navajo and Zuni Areas



Northern Navajo Medical Center

Chinle Comprehensive Health Care Facility

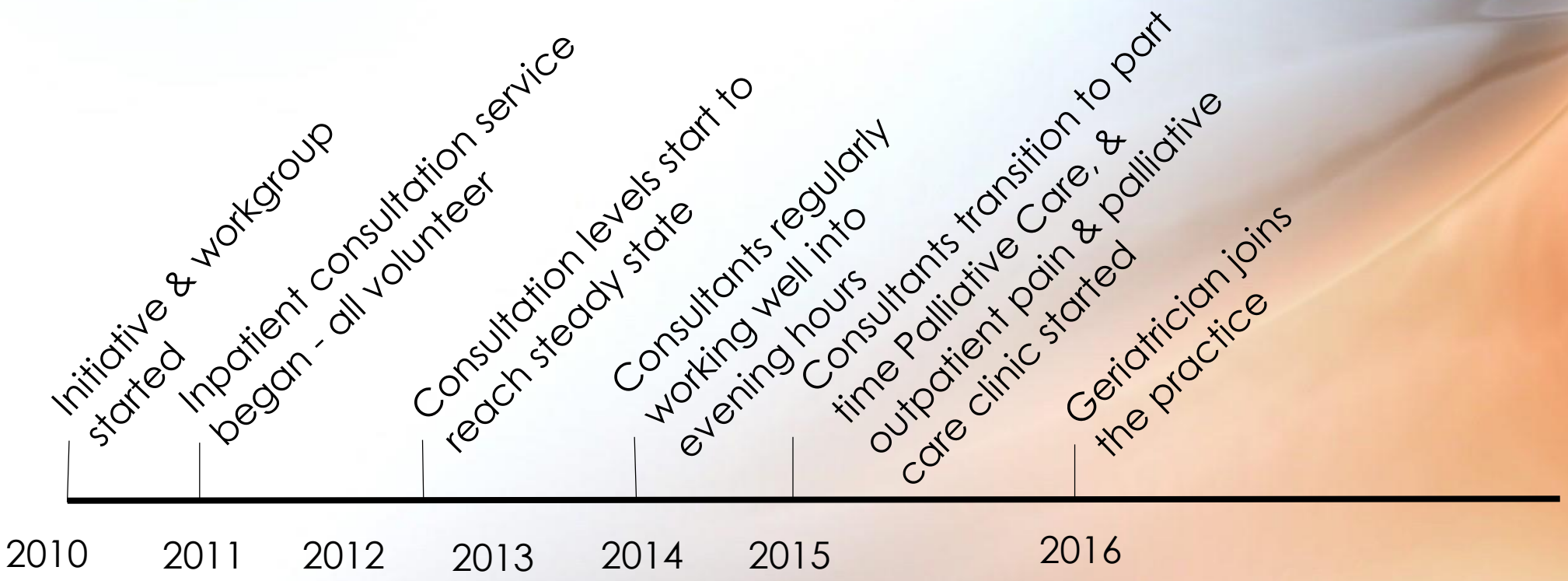
Gallup Indian Medical Center

Zuni Comprehensive Healthcare Facility

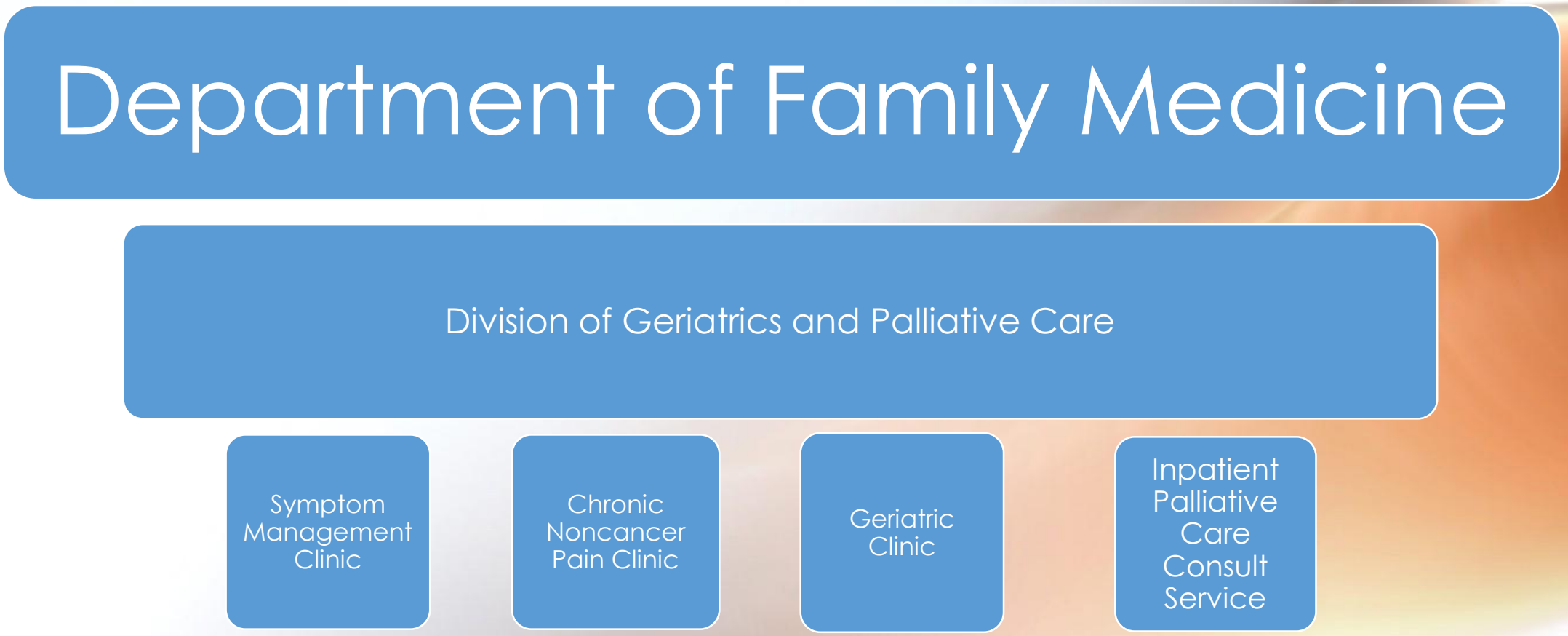
Gallup Indian Medical Center

- 77 bed facility with attached outpatient clinics
- 90 Providers
- Patient population 45,500
- Serving mostly Navajo (Diné) and Zuni Pueblo patients

Geriatrics and Palliative Care Program at Gallup Indian Medical Center



Division of Geriatrics and Palliative Care



Palliative Care at GIMC

- Inpatient consults
- Outpatient clinics
- Bi-weekly interdisciplinary team meetings
- Monthly workgroup meetings

Team members

- 3 physicians = total 2 FTE, dedicated social worker
- In kind members
  - Patient advocates
  - Dieticians
  - Case managers
  - Benefits coordinators
  - *Nurses
  - *Pharmacists
- Team members are largely from the community served, including one physician

Inpatient consults

- Doctors, nurses, other team members initiate consults
- Hospitalist gives consent
- Hours Monday to Friday, 8-5
  - Family meetings often conducted after hours
- Typical service has 4-7 patients
- Language interpretation by patient advocate or social worker

Outpatient PC Symptoms clinic

- 4 days a week
- Up to 6 30-min appointments per day, 10AM-2PM
- Referrals from providers, other Navajo Area hospitals, inpatient service follow ups
- Home visits seen as needed
  - 1-4 per month

Biweekly meetings

- Team members participate in interdisciplinary discussion
- Physicians give medical updates and seek input on management
  - Inpatient consults
  - Active outpatient consults
- Team members suggest new consults
- Deaths reviewed and informally memorialized

Monthly GPC Workgroup Meetings

- Interdisciplinary
- Program updates
- Presentations from hospices, community links, and other partners
- Palliative care projects
- Fundraising
- Ceremonies for program expansions, healing, maintenance

Community links and involvement

- GIMC GPC Workgroup
- GIMC Office of Native Medicine
- GIMC Patient Advocates
- Navajo Tribal Community Health Representatives
- COPE Cancer Coalition
- Hospices in Gallup

COPE
Community Outreach & Patient Empowerment

GIMC Palliative Care future directions

- Salaried positions
  - Pharmacist
  - Nurse specialist
- ER consults
- Nursing home consults
- ICU & surgical consult triggers
- Trailer project

Palliative care consults

- Goals of care
- Advance care planning
- Symptom management
- Patient support
- Family support
- Bereavement

Goals of care (GOC)

- Most frequent reason for consult
- Estimate prognosis, share if patient allows
- Find out what the patient's values are:
  - Ask patient what is most important
  - Ask family if patient unable to say
- Is the proposed plan of care compatible with the patient's values?
- Will there be unacceptable suffering if all available medical and/ or surgical treatments is given?
- With permission of the patient/ family, suggest a plan that takes into consideration that which is important to the patient

Advance care planning

- Def: Making decisions about the kind of healthcare you would want if you become unable to speak for yourself
- Based on personal values and beliefs
- Find out about and decide what types of life sustaining treatments are available
- Communicate decisions with loved ones
- Put decisions in writing:
  - New Mexico MOST Form
  - Other advance directive document

New Mexico MOST Form

- **M**edical
- **O**rders for
- **S**cope of
- **T**reatment

- New Mexico's version of the nationwide POLST, however NM version is a form of advance directive
- Form is scanned into the electronic record, original bright green copy goes with patient
- www.nmmost.org

Symptoms

- Many potential symptoms at end of life
  - Pain
  - Shortness of breath
  - Delirium
  - Fatigue
  - Depression
  - Constipation
  - Dry mouth
  - Anorexia, lack of appetite
  - Spiritual distress/ existential suffering
  - Death rattle

Managing Common Symptoms

- Pain: Multi-modal treatment with medication and non-drug approaches
- Shortness of breath: Morphine is most common drug; oxygen if oxygen saturation is low
- Delirium: Address cause(s) first before medication
- Constipation: Prevention with bowel regimen when opioids prescribed
- Offer spiritual support for patient and family compatible with their beliefs
- Death rattle: Distressing, not harmful, medications

Patient and Family Support

- Patient autonomy: patient receives health information and makes healthcare decisions unless:
  - Patient lacks capacity or,
  - Patient wants to defer to a chosen healthcare proxy
- Skills in difficult conversations:
  - Breaking bad news
  - Dealing with emotion
  - Helping patient develop **prognostic awareness**
- Above all, allow and foster **hope**
- Palliative care treats the family as well as the patient

Spiritual Support

- Office of Native Medicine
- Clergy arranged from GIMC clergy list
- Traditional practitioner, clergy, pastor, or priest arranged by family

Bereavement

- Bereavement cards signed by palliative care team members sent to family
- Selected cases: Families meet with palliative care team to debrief
- Phone calls
- Cancel upcoming appointments

Case #1 (Alice)

- 90 year old woman admitted to the hospital with decompensated NASH cirrhosis
- Bedbound, with anasarca, but alert and eating
- Palliative Care consulted for goals of care

Case #1

- Goals: reduce swelling & return home with her daughter
- “Navajos don’t talk about death”
- Patient met alone with patient advocate
- “My time is approaching”
- Expressed an interest in going home on hospice
- Did not want to die at home

Case #1

Case #1

- Treated with diuresis and large volume paracentesis
- Discharged home with daughter
- No hospice available in her area
- Palliative Care made home visits
- Two months later: no longer eating, sleeping most of the day
- Admitted to GIMC comfort care room for end of life care
- Died two days later

What makes Alice unique

- Cultural avoidance of home death
- Need for interpreters
- Remoteness of homes
- Lack of electricity and running water
- Poor road conditions
- Thoughts can create reality
- Poverty

Case #2 (Benson)

- 68 year old man with recently diagnosed renal cell carcinoma
- Attended local COPE cancer survivorship conference
- Many questions about his diagnosis and concerns about his care
- Agreed to come to outpatient Palliative Care clinic

Case #2

- In clinic, expressed anxiety about his diagnosis
- “How do you know it’s cancer if we don’t do a biopsy?”
- Underwent traditional treatment & wanted to know if his tumor was smaller

Case #2

- What more would you want to know?
- What are some ways you might be able to help him understand his illness?
- How might Palliative Care services help this patient?

Please discuss with your neighbor.

Case #2

- Diagnosis & risks of biopsy discussed
- Scans reviewed, showing stable tumor size
- Provided letter requesting a support person come to his urology appointment

Case #2

- Brought his medicine man to the urology appointment
  - Interpreted & assisted with decision-making
- Agreed to nephrectomy & underwent surgery with no complications
- No evidence of residual disease
- Still comes occasionally to outpatient clinic

Questions?

Ahéhee'!