End of Life Care in NC

Introduction to Hospice and Palliative Care Services

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We’ll touch on...

- Lay of the land- some demographic changes
- Cost and Quality imperatives
- Services provided
- Room for improvement
In North Carolina, the population of people age 65 and older grew from 1.2 million in 2010 to 1.6 million in 2016, an increase of 27%. The NC Office of State Budget and Management estimates a rise to 2.3 million in 2030 and 2.6 in 2037.
In 2016, 15.5% of North Carolina’s population was 65 or older.

University of Virginia, Weldon Cooper Center for Public Service for Public Service

Projected NC population proportions 65 & older

- 2020: 18%
- 2030: 21%
- 2040: 22%

https://demographics.coopercenter.org/national-population-projections
Aging and Cost of Care in NC

• In 2012, the cost of health care for North Carolinians 65 & older was $25 billion
• In 2037, the projected cost will be $69 billion
• 180% increase

http://www.ncmedicaljournal.com/content/79/1/66.full
Iceberg at End of Life with Advanced Life Limiting Illness
Capital and Social Costs need system change

Clinical Care costs are visible and measurable through claims
- CMS
- ACO Accounting (Delivery-Labor)

Social and Family Costs are not visible and measurable through claims
- Insurance premiums
- OOP average annual expense
- Business outlay of Non-Profit svcs
- Time conversion for work effort loss
- Time conversion for caregiver burden
- Caregiver and family impact

Explicit and Implicit Care provided
- Private Insurance
- Long Term Care (Private)
- Out of Pocket Expense (caregiver & family)
- Employment (Absenteism – Presenteeism)
- Housing (substandard)
- Social Services (nutrition, elder neglect enforcement)
- Home Health Coverage
- Independent living accommodations

Hospital + SNF + Hospice + some Home Health
THE DAD PLAN

WHAT HE BRINGS IN EACH MONTH $4,500

WHAT HE'LL NEED SOON $6,000

WHAT INCLUDES

HOME CARE AIDE

MEDICINE

MEDICARE

FOOD & UTILITIES

FINANCIAL SHORTFALL: $1,500

HOW TO COVER IT ??

ME

SIS

$500 $500

MEDICAID ?? (NOT YET WE HOPE...)

STATE PROGRAMS?

SELL THE CAR?
Nearly one quarter of adults in North Carolina provide regular care or help to an older adult with a disability or illness. Of these caregivers, more than half are employed and balance work and caregiving. (AARP) In addition, in 2015, the ratio of potential caregivers—people aged 45-64—to those over the age of 80 was eight-to-one. By 2030, there will only be 4 potential caregivers for every older adult in the state. (NCIOM)
Today
There are about 7 caregivers for each person 80+

2030
There will be about 4 caregivers as boomers reach 80

2050
There will be about 3 caregivers as Generation X hits 80

By the Generations
Older generations now have lots of boomers to care for them. But with lower rates of marriage and fewer children, the baby boom generation (born 1946 to 1964) and Generation X (1965 to 1979) will have smaller pools of caregivers.
Cost & Quality as Motivators

- High cost of end of life care.
- Small numbers of patient with high utilization

Almost one-third of Medicare expenditures are attributable to the 5 percent of beneficiaries who die each year.
About one-third of expenses in the last year of life are spent in the final month

- End of life care is 21% of Medicaid costs in North Carolina (2.6 billion out of $12.4 billion)
  http://www.ncmedicaljournal.com/content/79/i/43.full

- System in “default”- we will do everything to everyone
Quality of Care Imperative

- 70% die in hospitals or long-term care
- Aggressive and often futile therapeutic interventions in the last weeks of life
- 40% have severe pain prior to death
- Unmet needs for symptom management and support
- 31% families report major financial hardship because of terminal care costs
Quality deficit

- The average patient has 3 care transitions in last 90 days of life

- 30% of Medicare decedents have at least one ICU stay in the last month of life

- Mismatch between what health care provides and what seriously ill people need

- Family dissatisfaction with end-of-life care received by their loved ones
PALLIATIVE CARE

An added layer of support

- Care to improve the quality of life for patients with serious illness
- Focus:
  - Symptom management
  - Communication & Decision-making facilitation
  - Support for patient and family
- **Co-exists with disease-based evaluation and treatments**
All hospice is palliative care, but **not all** palliative care is hospice.

**Hospice** is a model of palliative care restricted to terminal illness. **Palliative care** is appropriate at any age and at any stage in serious illness.
Palliative Care – Hospice Intersection

Education in Palliative and End-of-Life Care (EPEC): www.epec.net
Palliative Care=Best Care

- 151 patients with metastatic lung cancer randomly assigned to get either oncology treatment alone or oncology treatment with palliative care.

- Palliative care group reported less depression and happier lives as measured on scales for pain, nausea, mobility, worry and other problems.

- Substantially fewer of them opted for aggressive chemotherapy as their illnesses worsened and many more left orders that they not be resuscitated in a crisis.

- They typically lived almost three months longer than the group getting standard care, who lived a median of nine months.

Temel et al. Early Palliative Care for patients with Non-Small-Cell Lung Cancer. NEJM 2010; 363: pp.733-42
Palliative Care Consultation

- Primarily hospital based
  - 70% of mid/large sized hospitals in NC
  - Some outpatient or nursing home programs
  - Consult service: MDs, NPs, SW, Chaplain

- Reasons for Consult:
  - Symptom assessment & management
  - Patient and family support
  - Facilitate communication & decision making
  - Information needs
  - Establish, clarify goals of care
Palliative care has historically been provided in the inpatient hospital setting or in hospice under the Medicare hospice benefit.

Palliative care historically has not been provided in other community settings, where the majority of patients living with serious illness would benefit from its availability.
community-based palliative care models

- “bridging programs”; Advanced Illness Management
  - Providing longitudinal, community-based PC
  - comprehensive medical/psychosocial assessment
  - coordination, advance care planning, communication of preferences to providers
  - palliative care, focusing on comfort as well as the psychological, social and spiritual well-being of patients and families.
- In concert with standard care to assess and address multidimensional symptoms
- Coordination of care, streamlining the transition from palliative to end-of-life care
Initiative Objectives

1. To enhance patient autonomy through advanced care planning communication in primary care
2. To enhance access to hospice, palliative care and other supportive care services for seriously ill patients
CCNC Palliative Care Initiative Strategies

Systems to support the PCMH

- Identification
  - PC indicator: claims data analytics, high mortality risk, propensity score

- STAFFING
  - PC Coordinator and Physician champion in each region
  - PC 101 and communication trainings
  - Telephonic support via Health Coaches
  - Statewide workgroup

- Provider education (recognize and standardize)

  - Would you be surprised? The longer you have known the patient...
  - Sensitize clinical judgment (providers and care management staff)
  - MOST form (POLST paradigm)
Develop systems to support the PCMH

- **Communication Tools**
  - Palliative care questions in CMIS
  - Respecting Choices / VitalTalk – communication skills
  - Goals of care discussions (Longevity, Function, Comfort)

- **Coordination of QI efforts with community resources**

- **Comprehensive Care Team- partnerships with local HH&H**
  - meet the complex needs of patients who were not yet eligible or not yet ready to accept hospice - aka “home based palliative care”
  - Leveraging the local expertise
ROI

- In nearly every quarter leading up to their death date, patients in the intervention group had fewer inpatient days, more hospice days, and lower costs.

- Average cost savings were $1,661 per patient, per month. Overall, there was an estimated $2.0 million in savings among the 207 patients receiving PC intervention.

Fischer J, Thomas J, and Jackson C. (November 2015). Effect of CCNC’s Palliative Care Initiative for Non-Dual Medicaid Recipients. CCNC Data Brief No. 6, Community Care of North Carolina, Inc.: Raleigh, NC
Palliative Care Program Hospital Costs per Month and Satisfaction Score

NET PROMOTER SCORE
93%

Accountable Care Organizations Represented in North Carolina (MSSP & NextGen)

(Based on Provider Attribution)

- 0 = 6 counties
- 1-2 = 57 counties
- 3-5 = 33 counties
- 6-9 = 4 counties

Toward ACO Accountable Care Consortium
Hospice

✅ Philosophy
✅ Home Care Program
✅ Insurance Benefit

• Life limiting illness
• Focus on care not cure
• Unmet needs
• Intensive pain and symptom management
• Spiritual & social support
• Desire to remain at home
Hospice team - INTERDISCIPLINARY
2017 Hospice- North Carolina Data

- 44% of decedents received hospice in NC (up from 30% in 2006)
- 48% nationally -NHPCO 2017
  - 22% NC Medicaid
- high of 58% UT and low of 23% PR
- Davie, Yancey, Polk (95%, 88%, 87%)
- Orange, Pitt, Hyde (25%, 24%, 21%)
Hospice Utilization Rates

Counties designated by quartile

- Highest Quartile (38%-66%)
- Second quartile (29%-37%)
- Third quartile (23%-28%)
- Fourth quartile (16%-22%)
- Lowest quartile (6%-22%)
<table>
<thead>
<tr>
<th>Deaths by Length of Stay</th>
<th>2017 NC Data Count of Patients</th>
<th>2017 NC Data % of Patients</th>
<th>2016 NC Data % of Patients</th>
<th>2016 Medicare NC</th>
<th>2016 Medicare National</th>
</tr>
</thead>
<tbody>
<tr>
<td>% Died &lt; 7 Days</td>
<td>16,147</td>
<td>38.2%</td>
<td>37.2%</td>
<td>35.5%</td>
<td>36.4%</td>
</tr>
<tr>
<td>% Died &gt; 180 Days</td>
<td>3,693</td>
<td>8.7%</td>
<td>8.7%</td>
<td>5.0%</td>
<td>5.4%</td>
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Comment: Having such a high number of patients die in less than 7 days impacts the hospice team’s ability to deliver the full range of services to a patient to provide the best hospice experience. Use this information in education to referral sources, including a renewed emphasis on Advance Care Planning discussions between providers, patients and their families.
In 2000 60% of hospice admissions were Cancer
Hospice Improves Quality

- Higher family satisfaction compared to terminal care in hospital or nursing home
- Decreases hospital transfers and improves pain control
- Improves family satisfaction with pain control, care for emotional and spiritual needs

Sources:
Determining Prognosis

- Major barrier to hospice referral and discussions
  - Physicians afraid of being wrong
  - Data indicates that physicians overestimate prognosis (as much as by a factor of 5) - consistently!

- Best prognostic data exists for cancer

- The longer you have known the patient and the more recently that you have seen them....

- Most (but not all) patients want to discuss

- Palliative care consultations are NOT dependent on prognosis

Source: EPERC, Medical College of Wisconsin
General Predictors: applicable to all diagnoses

- Underlying chronic life-limiting disease
  +
- Progressive loss of function (ADLs)
  +
- Increasing frequency of hospitalization with no improvement in function
Typical Chronic Illness Trajectories
Who is “at risk”? 

Patients with advanced serious illness:

- Incurable cancer,
- Advanced chronic organ system failure (COPD, CHF, renal failure, liver failure)
- Progressive neurologic conditions (dementia, Parkinson’s, ALS, major stroke)
Who else is “at risk”? 

Patients with: 

- High risk of death during the coming year – “Would you be surprised if this patient died in the next year?”
- Who prioritize goal of comfort
- Frequent hospitalizations
- Recent functional decline
"There's no easy way I can tell you this, so I'm sending you to someone who can."
## Hospice vs. Palliative Care

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<th>Comparison</th>
<th>Hospice</th>
<th>Palliative Care</th>
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<td><strong>Pain &amp; Symptom Management</strong></td>
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<td><strong>Communication/Decision Making</strong></td>
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<tr>
<td><strong>Comprehensive insurance benefit: Meds/Equipment/Home supports</strong></td>
<td>Limited insurance coverage for physician consultation</td>
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</tr>
<tr>
<td><strong>Prognosis &lt; 6 months if natural course</strong></td>
<td>Independent of Prognosis</td>
<td>Independent of Prognosis</td>
</tr>
<tr>
<td><strong>Goal: exclusively comfort. Avoid hospitalizations</strong></td>
<td>Co-exists with disease-based evaluation/treatment, hospitalizations</td>
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<td><strong>Where:</strong> Home, long-term care, inpatient facility beds</td>
<td>Where: primarily hospitals, long-term care, outpatient clinics</td>
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Watch our Language

To remove barriers to good care, we need to talk about palliative care with language that has relevance to patients, families, and health professionals:

- Added layer of support;
- Work with patient’s doctors;
- Relieve pain, symptoms, stress of serious illness;
- Any age, any stage, any dx;
- Alongside curative/life prolonging Rx
Putting it in writing....

- Health Care Power of Attorney
  - who would make a good surrogate
  - do they know how you feel, what is important to you or how you would make decisions?

- Living Will

- Medical Orders for Scope of Treatment (MOST)
Medical Orders for Scope of Treatment (MOST)

- More than a DNR order
- Guide care even when patient has not arrested
- Options to receive or withhold treatments
- Avoid inappropriately limiting or providing other types of treatments
Thank you! Go Heels!