Objectives

At the conclusion of this presentation, the participants will be able to:

- Describe the growth in end of life care services in hospice and palliative care and the need to continue to improve access to end of life care and services.
- Describe differences between palliative care and hospice care.
- Describe an example of a successful integrated hospital, hospice and community based palliative care program.
- Identify barriers in developing an integrated palliative care program and useful strategies to address them.
- Discuss the research-based Decision Aid for Palliative Referral (DAPR) as a screening tool to assist clinicians in all settings in identifying patients who may be appropriate for palliative care services.
- Describe strategic opportunities and considerations for home health agencies, hospices, hospitals and health systems in the development of an integrated palliative care program.
End of Life Care in America

• The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) (RWJ) 1986 – 1994 put a spotlight on end of life care in the US

• “Americans die in hospitals, often alone and in pain, after days or weeks of futile treatment, with little advance planning, and at high cost to the institution and the family.”

End of Life Care in America

• After the failure of SUPPORT the RWJ funded three very important grants. The goals moved from creating health care provider specific solutions (ex: Hospitals) to engaging communities to enact overall social change and connect these changes to the health care community.
  ➢ Last Acts
    ✓ Community/State Partnerships
  ➢ Promoting Excellence in End-of-Life Care
    ✓ Care and cure could be provided simultaneously
  ➢ Education in Palliative and End-of-Life Care (EPEC)
    ✓ Developed by the AMA to reach all practicing MDs
    ✓ ELNEC Nursing Education

• Institute of Medicine of the National Academies (IOM) published Approaching Death: Improving Care at the End of Life
  ➢ Assisted as another catalyst for change
End of Life Care in America

- Physicians and nursing training lacked education about how to care for dying patients
- Hospice care was seeing only a small fraction of patients
- Legal and Ethical practices started to be questioned
  - Karen Ann Quinlan
  - Cruzan Case
  - “Death with Dignity”
  - Jack Kevorkian
- Patient Self Determination Act

Changing End of Life Care in America

- Late 1990’s saw introduction of changes to Medical Textbooks to include palliative care
- American Board of Hospice and Palliative Medicine was formed (ABHPM) Now AAHPM
  - Licensing and Credentialing in Hospice and Palliative Care
  - Fellowships
- There are now over 124 active fellowship programs in hospice and palliative care,
  - In the decade between1996 and 2006, more than 2,100 physicians became certified.
- Currently over 4,100 Members AAHPM
## Changing End of Life Care in America

- RWJ provided funding for nursing education in hospice and palliative care
- Changes in nursing education in BSN programs
- End of Life Nursing Education Consortium (ELNEC)
- *Founding the Hospice and Palliative Nurses Association (HPNA)*
  - Certification programs nurses, aides, administrators
  - Education for clinicians

## Center to Advance Palliative Care

- The Center to Advance Palliative Care (CAPC) was formed with these goals:
  - Increasing the number of hospitals with the capability to provide palliative care
  - Have hospital based palliative care be standard practice in comprehensive patient care
  - Provide leadership for the creation of palliative care standards
  - Provide leadership for the creation of training centers where providers would train other providers
- Resources
  - Guide on Implementing a Palliative Care program
  - Numerous other resources on End of Life Care
What’s been the progress?

- Dartmouth Atlas Reports from 2003 to 2007
  - More patients spending less time in hospital at the end of life
  - More patients being referred to hospice
- Widespread variation exists in the percentage of hospital deaths and the average number of hospice days per patient in the last 6 months of life

Growth in Palliative Care in Hospitals

<table>
<thead>
<tr>
<th>Prevalence of U.S. Hospital Palliative Care Teams: 2000–2012</th>
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</thead>
<tbody>
<tr>
<td>Number of Hospitals (50+ Beds) with Palliative Care Teams</td>
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<tr>
<td>658</td>
</tr>
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</table>

- CAPC Annual Survey Summary – July 2014
Growth in Number of Hospice Providers

What is left to do?

• Most Americans when asked where they would prefer to die at home in their own beds
• 2012 Medicare claims data reflects that only 44% of decedents died on hospice this is up from 18.1% in 2001
• It’s not enough
  • Focus of change has really been in hospitals
    • Costs of EOL care is huge
    • Opportunities for clinical practice changes
    • Opportunity to impact cost of care
Palliative care is patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information and choice (National Consensus Project Definition).

Hospice is Palliative Care but is confined to end of life for patients with a 6 months or less prognosis.

Models of Palliative Care

- Hospital Based
  - Reduction in end of life costs
    - ICU stays
    - Overall costs of Care
    - Mortality Reduction

- Consultative Models
  - MD and NP Driven
    - Pain and Symptom Management
    - Introduction of Advance Directives

Variable
- Large teams in health systems
- Sole providers in smaller organizations
### Models of Palliative Care

#### Outpatient Palliative Care
- Cancer center linkages
- Chronic Care

#### Medical Practices
- Palliative care based
- Nursing home

#### Hospices
- “Bridge” Program Evolution
  - Palliative Programs outreach into community
- Contracting out Hospice MD/NP to hospitals to provide palliative care

#### Models of Palliative Care

- Home Health Agency
  - Serious or Chronically Ill patients
  - Coordination with hospice – referral and shared case management
Payment Models in Palliative Care

- ($)  
  - Cost Saving  
  - Increase referrals

- Part B  
  - Physician and NP

- One time/One Visit payment Hospice Consult

- Traditional Medicare  
  - Continuation of Skilled Home Care

- Philanthropy

- New Payer relationships emerging

Future Models and Opportunities

- Medicare Care Choices Model  
  - Demonstration for patients seeking curative and palliative care

  - Small payment $400 a month for hospices to case manage patients

  - Provider hope – positive influence into future payments

  - See results........

- ACO (Accountable Care Organizations)  
  - Utilizing Palliative Care in ACO models

    - Demonstrated use of cost savings
Strategic Opportunities for Palliative Care Programs

- Hospital/Health System collaboration/affiliation
  - Chronic disease management
  - Hospital mortality and readmission rates
  - Cost reduction and LOS opportunities
- Home Care/Hospice collaboration
- Accountable Care Organizations
- Medicare Care Choices Model
- Data Collection! Prove your worth!

Opportunities for the Experts

- Home Care
  - Experts in managing chronic illness
  - Prevention of Hospitalizations
- Hospice
  - Experts in managing pain and symptoms
  - Team level of care

Being persistent in continuing to improve end of life care…. like the persistence of water and time created a wonder here in Arizona
History of Middlesex Hospital Hospice and Palliative Care Program

• Began with hospice inpatient services and contracted VNA
• Hospital bought the local VNA and established certified home hospice program
• Palliative care started with a hospice nurse attending CCU rounds
• RN position established to address end of life issues, advance directives, symptom management

• Quality of Life team established to avoid being associated with hospice
• Consults completed throughout the hospital
• Palliative home patients with a life limiting illness and prognosis of less than one year managed by the hospice team
### Middlesex Hospital Homecare

**An Example of Integrated Palliative Care**

- Home care and Inpatient Component- one program for hospice and palliative care
- Homecare agency is a department of the hospital
- 12 Bed inpatient unit dedicated for hospice or palliative care patients
- All staff are oriented & trained in hospice and palliative care
- 70% have certification All Staff

### Palliative Care at Middlesex Hospital

- Home care team consists of 2 dedicated nurse case managers and one part time LCSW
- Inpatient team consists of part time APRN, CCU LCSW, Chaplain and Medical Director
- Average Census for homecare is 30 patients
- Average inpatient palliative consults 50/month
Palliative Care in the Hospital Setting

- Physician referral

- Initial screening to gather information and goals of referral

- APRN/Medical Director completes consult

- Documentation of patient goals of care, recommendations for symptom management and discharge plan

Management of Palliative Care Across the Care Continuum

**Inpatient Setting:**

- Follow up provided daily by member of Palliative Care team for inpatient

- Interdisciplinary team meets twice a week for inpatient rounds

- Transition to inpatient unit for symptom management that is uncontrolled

- Discharge planning recommendations
### Management of Palliative Care Across the Care Continuum

#### Home care Setting:

- Referred from inpatient Palliative care team- meets skilled need and homebound criteria
- Discussed monthly at IDT
- SNF- consultative palliative care service offered
- Transition to Hospice Care

### Communication

- Home care and Inpatient staff located on the same floor
- Report to outside agencies when patient is discharged from inpatient settings
- Report to hospital staff if patient transitions back to hospital
- Transition to hospice care earlier
Lessons Learned

- Lack of understanding and knowledge by health care community and patients
- Education needed across the care continuum
- Palliative Care is a “dance”- Expert discussion- Time to digest – Decision making occurs
- Need to keep prevent Palliative Care from becoming Hospice care
- MANY questions about what palliative care is and who is appropriate

Decision Aid for Palliative Referral (DAPR)

- Need to accurately identify patients who may benefit from palliative care services
- Screening tool at the time identified hospice appropriate patients
- DAPR is a tool to assist direct care nurses and MSW in talking with the attending clinician about obtaining palliative care referrals
- Available to all clinical staff
DAPR Design Process

- No validated palliative referral screening tools

- Designing the DAPR:
  - National Quality Forum guidelines
  - The Joint Commission
  - Center to Advance Palliative Care (CAPC)

DAPR - Primary Criteria

- Disease process:
  - Serious illness - usually progressive, often life-limiting, advanced process in major organ systems and metastatic cancer, includes option for "other" must specify
  - Screening process stops if patient does not meet primary criteria
Distress indicators; many apply to family also align with NQF Framework Domains and Preferred Practices:

- Physical
- Emotional
- Social/Financial
- Existential/Spiritual
- Ethical

DAPR Psychometric Testing

- Content Validity:
  - Experts in palliative care (multidisciplinary)
  - response rate of 10/10;
  - n=9 one form with incomplete responses

<table>
<thead>
<tr>
<th></th>
<th>primary</th>
<th>secondary</th>
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<tbody>
<tr>
<td>S-CVI/ave (&gt;0.8)</td>
<td>0.98</td>
<td>0.92</td>
</tr>
<tr>
<td>I-CVI (&gt;0.78)</td>
<td>0.89-1</td>
<td>0.67-1.0</td>
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DAPR Psychometric Testing

- Inter-Rater Agreement:
  - 3 case studies with sim-lab video scenario
  - 37 participants; 34 RNs and 3 MDs
  - Randomly assigned to one of the three cases

<table>
<thead>
<tr>
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<th>secondary criteria</th>
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<tbody>
<tr>
<td>case 1 (N=14)</td>
<td>98%</td>
<td>92%</td>
</tr>
<tr>
<td>case 2 (N=9)</td>
<td>100%</td>
<td>88%</td>
</tr>
<tr>
<td>case 3 (N=14)</td>
<td>98%</td>
<td>81%</td>
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Retrospective Chart Review

- Palliative Referrals (N=75)

<table>
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<th>Primary Score</th>
<th>Secondary Score</th>
<th>Overall</th>
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<tbody>
<tr>
<td>Palliative admits (n=45)</td>
<td>2.27</td>
<td>3.20</td>
<td>5.42</td>
</tr>
<tr>
<td>Hospice Admits (n=23)</td>
<td>2.26</td>
<td>4.43</td>
<td>6.70</td>
</tr>
<tr>
<td>Not admitted (n=7)</td>
<td></td>
<td></td>
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<tr>
<td>4-died</td>
<td>2.29</td>
<td>2.71</td>
<td>5.00</td>
</tr>
<tr>
<td>2-refused</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>1-d/c</td>
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Overview of the DAPR

- Tool is scored with recommendations for referral or follow-up
- If referral is indicated, discussion is held with the attending physician who ultimately decides if a consult is placed
- Review Sample DAPR Tool (Handout)

Next Steps

- Dissemination of information and the tool to hospice, home care and hospital clinicians
- Nursing Grand Rounds/ Hospital Grand Rounds
- Article for nursing journal publication
- Recommended to screen:
  - ED patients who live at SNF
  - Oncology patients, inpatient and outpatient
  - CCU patients after 48 hours
Potential Partnerships for Palliative Care Referrals

- Cancer Center
- Chronic Care Management
- Skilled Nursing or Assisted Living Facilities
- Community outreach for education- churches, senior centers

Case Study #1 (Review Using Sample DAPR)

- Sixty year old woman with a history of COPD, CAD, chronic back and neck pain, chest pain, HTN, DM type II, Depression, Anxiety, Dependent Personality Disorder, indication of probable old silent stroke (CVA), Dyslipidemia, Diverticulitis, Right Lower Extremity Cellulitis, Anemia; Hepatitis per patient report.
- Presented to the ED with dyspnea, fatigue, and chest discomfort, recently admitted for same, ruled-out for Acute MI. 3 other admissions in the past 6 months.
- Lives at home alone with Home Health (VNA) support.
Case Study #2 (Review Using Sample DAPR)

- Eighty-year-old woman with a history of CAD, CHF, COPD, DM, Metastatic Lung Cancer (bilateral) which progressed through chemo and is currently not being treated because of absence of feasible therapeutic options.
- Presented to the ED with 2 day history of diarrhea, new onset left sided headache near the eye, and chronic but exacerbated dyspnea and fatigue.
- Lives at home with her husband.
<table>
<thead>
<tr>
<th>Name</th>
<th>Title</th>
<th>Organization</th>
<th>Contact Information</th>
</tr>
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<tr>
<td>Melanie Cama</td>
<td>BSN, RN, CHPCA</td>
<td>Hospice and Palliative Care, Program Director</td>
<td><a href="mailto:melanie.cama@midhosp.org">melanie.cama@midhosp.org</a></td>
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<tr>
<td>Julia H Maroney</td>
<td>RN MHSA</td>
<td>Senior Manager</td>
<td><a href="mailto:jmaroney@simione.com">jmaroney@simione.com</a></td>
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<td>802-733-5102</td>
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</tbody>
</table>
**DRAFT Decision Aid for Palliative Referral (DAPR)**

**PRIMARY CRITERIA:** DIAGNOSIS of potentially life limiting illness or chronic illness with evidence of progression

directions: select ALL that apply. **Score 2 points for each**

- Advanced Cancer  
- Metastatic disease  
- Advanced Cardiac Disease  
  - Cardiomyopathy  
  - Severe or recurrent heart failure  
  - Valvular disease not appropriate for surgery  
  - Severe pulmonary hypertension  
  - Severe CAD not a candidate for revascularization  
  - High grade AV block and declines pacing therapy  
  - Candidate for heart transplant or LVAD  
- Advanced Pulmonary Disease  
  - Acute on chronic respiratory failure  
  - Hypoxemia or Hypocapnia  
  - Recurrent pulmonary infections  
- Advanced Kidney Disease  
  - Chronic Kidney Disease stage 4 or 5  
  - GFR less than 30  
- Advanced Liver Disease  
  - Ascites despite max diuretics  
  - Hepatic Encephalopathy  
  - MELD score greater than 18  
- HIV disease with wasting syndrome  
- Progressive Neurological Disease (examples)  
  - ALS  
  - Parkinsons with Lewy Bodies  
- Stroke  
  - Persistent Altered Mental Status  
  - Dysphagia (failed swallow study)  
- Advanced Dementia  
  - Non-ambulatory  
  - Incomprehensible or very limited speech  
  - Dysphagia/ tube feeds  
  - Recurrent Infections (UTI, Pneumonia)  
- Other life-limiting condition  

(2 points each) Primary Criteria SCORE: _______ (Must meet primary criteria to continue to secondary criteria)

**SECONDARY CRITERIA:** Distress indicators. **Score 1 point for each**

### Physical/Psychological COMFORT Functional Status
- Uncontrolled or chronic symptoms that interfere with quality of life:  
  - pain  
  - dyspnea  
  - nausea/ vomiting  
  - constipation/ diarrhea  
  - rapid weight loss  
  - swallowing difficulty  
  - anxiety  
  - agitation  
  - fatigue  
  - irritability  
  - tearfulness  
  - confusion  
  - hallucinations  
- Marked change in functional or performance status (↓ by 20% or greater) in last 2 months  
- Permanent tube feeding for life sustaining purposes  
- Co-morbid disease of any major organ system:  
  - Cardiac  
  - Pulmonary  
  - Renal  
  - Neurologic  
  - Hepatic  
  - Skin (progressing or non-healing wounds)  
  - Cancer

### Social Communication and Decision Making Ethics
- Patient/family express concerns or distress related to health / illness (may include):  
  - fear  
  - anger  
  - guilt  
  - alienation  
  - despair  
  - grief (current situation or previous loss)  
- Limited support network (fewer than 3 people who are will or able to assist)  
- No Advance Directive and life support or end-of life care decisions may need to be made  
- Surrogate/ health care representative is distressed or ambivalent about making decisions  
- Code status: there is conflict about code status designation  
- Confusion or disagreement about prognosis, goals of care, or use of specific interventions  
- Ethical concerns

### Spiritual Existential
- As related to God, religion, or meaning to their life, patient or family express:  
  - alienation  
  - despair  
  - anger  
  - fear  
  - guilt  
  - grief  
- Hopelessness or spiritual abandonment  
- Patient or family express spiritual distress or question meaning of life  
  eg. "Why is this happening to me?"  "How could God do this?"

### Service Utilization
- 3 or more Emergency Department visits during the past 6 months  
- 2 or more Hospitalizations during the past 6 months  
- From Extended Care Facility and has history of ADL dependence or cognitive impairment  
- Admission is for recurrent symptomatic issues (eg. shortness of breath)

(1 point each) Secondary Criteria Score: _______  
SCORING: Primary Criteria _______ + Secondary Criteria _______ = SCORE _______

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