Meeting Patients Where They Are

Rodney Tucker, MD MMM
Chief Experience Officer, UAB Medicine
Director, UAB Center for Palliative and Supportive Care
No Financial Disclosures

Dr. Tucker is a speaker for the Studer Group in the realm of patient experience
Objectives

- Identify opportunities for promoting upstream incorporation of palliative care
- Discuss settings of care that meet patients where they are in their illness journey
- Discuss the differences between palliative care and hospice
Palliative care is specialized medical care for people with **serious** illness delivered by an interdisciplinary team.

- Relief from the **symptoms** and honors goals whatever the diagnosis
- Improve **quality of life** for both the patient and the family in **four domains of suffering**
- Appropriate at any age and at any stage of a serious illness provided concomitantly to other therapies
- **Extra layer** of care

https://www.capc.org/payers/palliative-care-definitions/
**PC vs Hospice**

**Palliative Care**
- Can be delivered along side curative care
- Don’t have to sign up for it
- Can be a long term care partnership
- Delivered by a team in clinic, home or hospital setting
- Not just end of life care

**Hospice**
- Payment mechanism
- Traditionally delivered at home or nursing home
- Have to sign up for it
- Primarily geared toward end of life; 6 months
Who is the Palliative Care team

- Doctors
- Nurse practitioners, Physician assistants
- Nurses
- Social Workers
- Pastoral Care
- Music therapists
- Pet therapy
- Massage therapists
- VOLUNTEERS
- Psychology, Counseling
- Nutritionist
- Complementary therapists
- Pharmacists
Four Domains of Suffering

- Physical
- Psychosocial
- Emotional
- Spiritual
What is Palliative Care?

Consumer Awareness About Palliative Care
How knowledgeable, if at all, are you about palliative care?

- Not At All Knowledgeable: 70%
- Somewhat Knowledgeable: 14%
- Very Knowledgeable: 5%
- Knowledgeable: 3%
- Don’t Know: 8%

*Data from a Public Opinion Strategies national survey of 800 adults age 18+ conducted June 5-8, 2011.*
Once informed, consumers say they would be very likely to consider using palliative care if they or a loved one had a serious illness.

*And how likely, if at all, would you be to consider palliative care for a loved one if they had a serious illness?*

<table>
<thead>
<tr>
<th></th>
<th>Age 25+</th>
<th>Age 65+</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very likely</td>
<td>63%</td>
<td>62%</td>
</tr>
<tr>
<td>Somewhat likely</td>
<td>29%</td>
<td>28%</td>
</tr>
<tr>
<td>Not too/ Not at all likely</td>
<td>6%</td>
<td>6%</td>
</tr>
</tbody>
</table>
### Quality of Life in Older Age

| % of U.S. adults who say each of these is important for a good quality of life in older age |
|---------------------------------|-----------------|-----------------|-----------------|
| Extremely | Very | Somewhat/not |
| Being able to talk/communicate | 49 | 44 | 7 |
| Being able to feed oneself | 45 | 44 | 9 |
| Getting enjoyment out of life | 44 | 46 | 9 |
| Living without severe, lasting pain | 43 | 44 | 12 |
| Long-term memory | 37 | 46 | 16 |
| Feeling what one does is worthwhile | 37 | 46 | 16 |
| Being able to dress oneself | 36 | 45 | 18 |
| Short-term memory for events today | 30 | 41 | 27 |

Source: Pew Research Center survey March 21-April 8, 2013. Q18a-h. Those saying “don’t know” are not shown.
So Why Do Healthcare Systems Care?

- Studies have shown significant impact on several quality measures such as respect and dignity, pain management, and overall satisfaction in the case of PC units.
- Palliative care consult services and units have consistently been shown to impact/lower direct cost of care per day when PC involved.
- Leaders in Patient and Family Centered Care model.
- Recognized that early palliative care intervention in advanced illness may extend life (NEJM 363;8;Temel, et al)
From Another Perspective:

Medicare per capita spending was nearly four times higher for decedents than survivors in 2014

Average Medicare per capita spending for decedents and survivors in traditional Medicare, 2014

- All traditional Medicare beneficiaries: $10,126
- Decedents: $34,529
- Survivors: $9,121

NOTE: Excludes beneficiaries in Medicare Advantage.
SOURCE: Kaiser Family Foundation analysis of a five percent sample of 2014 Medicare claims from the CMS Chronic Conditions Data Warehouse.
Many groups of patients with serious illness may benefit from an extra layer of care

Criteria and triggers are simply Guidelines

**ASK YOURSELF THE SURPRISE QUESTIONS**
The Surprise Questions

- Would you be surprised if my loved one died within one year?

- Would you be surprised if my loved one with a serious illness is readmitted to the hospital within three months?
Current State

- PC is fastest growing medical specialty in US
- >150% increase in hospital based programs over past 10-15 years
- Large majority of hospitals over 250 beds have some form of PC consult service
- Diagnosis of patients accessing PC and Hospice continues to evolve away from majority cancer as in the past
Access to Hospital-based Palliative Care

PALLIATIVE CARE GROWTH IN THE U.S.

As of 2012, 1,734 out of 2,844 hospitals with 50 beds or more reported a team. These teams are serving an estimated 6 million Americans.

The prevalence of palliative care in U.S. hospitals with 50 beds or more has nearly tripled since 2000, reaching 61 percent of all hospitals of this size.
PC Access By Region

[Map showing PC access by region in the United States divided into different grades: A, B, C, with specific states categorized under each grade.]
Challenges and Barriers

- Education re: diff between hospice and PSC
- Cultural beliefs re: dying (patients and providers)
- Provider shortage
- Difficulty in broadening the evidence base
- Rural locales
- Payment mechanisms
Avoidable Suffering Due to Dysfunction in Care System

Unavoidable Suffering Due to Treatment

Suffering Due to Diagnosis

What are Patients Experiencing?

Tom Lee, MD CMO
Press Ganey
Care Delivered vs. Care Experienced

- Hospital (HCAHPS)
- Clinics (PQRS CAHPS)
- ED (ED CAHPS)
- Surgery (OS CAHPS)

Patients Experience
Care Continuum

Hospital PCU Consult Svc
Clinics Supportive Care
ED Triggers Early Identification
Home In the Community

Palliative and Supportive Care Impact
Meeting Patients in Acute Care

- Consultation
- Inpatient unit
Care Continuum

- Hospital
- PCU Consult Svc
- Clinics Supportive Care
- ED Triggers Early Identification
- Home In the Community

Palliative and Supportive Care Impact
Meeting patients in the ED

- Rapid rapport; “Treat them and street them”
- Not the best place to have a PC conversation
- Role for enhanced EMR in order to find advance care planning documents/goals, etc.
- Can be pivotal to an organizations mission and care continuum if done right
- Requires rapid assessment and coordination
The Latest Site for Palliative Care: The Emergency Room

Atul Gawande
Care Continuum

- Hospital
- PCU
- Consult Svc

- Clinics
- Supportive Care

- ED
- Triggers
- Early Identification

- Home
- In the Community

Palliative and Supportive Care Impact
Meeting patients in the Community

- Clinic-based models
- Home-based palliative care
- Community entities – parish nurses, community health workers, navigators
- Nursing homes, assisted living
- “Telemedicine” models
- Hospice
Clinic based models

- Geographic clinic
- Embedded clinic e.g. in an oncology practice or cancer center
- Embedded expertise in primary palliative care in another specialty clinic e.g. heart failure
- Transitional clinics such as discharge clinics for quick follow up post hospitalization
Community Health Workers

- Established members of the community they serve
- “Natural helpers”
- Recruited by sites: “who in the community would you expect to have helpful guidance if…”
- Retired school teachers, cancer survivors, persons who had some medical exposure (worked desk at local MD office…)
**Lay Navigators**

- **EMPOWER** patients to take an active role in their healthcare
  - Identify resources
  - Recognize clinical symptoms
  - Understand disease and treatment
  - Engage in ACP/end-of-life discussions with their providers

- **Eliminate Barriers**
  - Link patients with resources to get to appointments
  - Connect patients to providers to address symptoms
  - Coordinate care between multiple providers

- **Ensure Timely Delivery of Care**
  - Help patients navigate the health care system
  - Assist with access to care
Patient Care Connect Program

- 12 cancer centers across 5 southeastern states
- ~40 lay (non-clinical) navigators
- Nurse site managers

University of Alabama at Birmingham Health System
Cancer Community Network (CCN)
Home-based Palliative Care

- Model of in-home nurse practitioner level primary palliative care
- Patients are referred to service by their PCP or by an algorithm for elevated 1 year risk of mortality
- The “customer” is the Medicare Advantage company – no copay or charge to patients/families/PCP’s
THIS IS THE WEB.
Pain Report

Pain is a sensory experience that is highly subjective to the individual. Pain may be acute or chronic and is characterized in various ways, according to duration, intensity, type (dull, burning or stabbing), source, or location in body.

What we've learned from patients who report Pain

- **Symptom severities**
  - Severe: 10,306
  - Moderate: 15,094
  - Mild: 10,070
  - None: 10,602

What patients report taking for the purpose of treating Pain

- Tramadol: 895
- Gabapentin: 805
- Ibuprofen: 593
- Lyrica: 560
- Hydrocodone: 500
- Cymbalta: 437

See all 7085 symptoms in the PatientsLikeMe system shared by patients just like you.
Effects of a Palliative Care Intervention on Clinical Outcomes in Patients With Advanced Cancer
The Project ENABLE II Randomized Controlled Trial

Marie Bakitas, DNSc, APRN
Kathleen Doyle Lyons, ScD, OTR
Mark T. Hegel, PhD
Stefan Balan, MD
Frances C. Brokaw, MD, MS
Janette Seville, PhD
Jay G. Hull, PhD
Zhongze Li, MS
Tor D. Tosteson, ScD
Ira R. Byock, MD
Tim A. Ahles, PhD

Context  There are few randomized controlled trials on the effectiveness of palliative care interventions to improve the care of patients with advanced cancer.

Objective  To determine the effect of a nursing-led intervention on quality of life, symptom intensity, mood, and resource use in patients with advanced cancer.

Design, Setting, and Participants  Randomized controlled trial conducted from November 2003 through May 2008 of 322 patients with advanced cancer in a rural, National Cancer Institute-designated comprehensive cancer center in New Hampshire and affiliated outreach clinics and a VA medical center in Vermont.

Interventions  A multicomponent, psychoeducational intervention (Project ENABLE [Educate, Nurture, Advise, Before Life Ends]) conducted by advanced practice nurses consisting of 4 weekly educational sessions and monthly follow-up sessions until death or study completion (n = 161) vs usual care (n = 161).

Main Outcome Measures  Quality of life was measured by the Functional Assessment of Chronic Illness Therapy–Fatigue (FACT-F) scale.
The key to spreading PSC and taking it to the next level is partnerships!

- Hospice and hospital
- Providers and Volunteers
- Cancer centers and hospitals and hospices
- Health Departments and hub providers/expertise
- Home care and hospice and PSC hub
- SNF and ALF and all the above
What you can do today

- Re-evaluate your assessment of loved ones with serious illness by asking the Surprise Questions
- Consider conversations around advance care planning
- Question and Investigate whether your hospital has palliative care services
Palliative care is restoring the art of medicine to the science of curing

Palliative care is about matching evidence with preference

Palliative care is about how we choose to live, not just prepare to die
Final Thought

- At the end of the day in order to meet patients where they are....we have to go there with them.
Questions or for more information:

Rodney Tucker, MD MMM

- rtucker@uabmc.edu
- www.palliative.uab
- 205-975-8197