Palliative care: a primer and focus on brain tumor

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The word on the street...

- What have you heard?
- What do you want to know?
“How familiar you are with the following terms?”

- **Palliative Care**
  - Familiar: 24%
  - Not Familiar: 71%

- **End-of-Life Care**
  - Familiar: 65%
  - Not Familiar: 33%

- **Hospice Care**
  - Familiar: 86%
  - Not Familiar: 13%

Regence Foundation/National Journal Poll #1: n=1000 American Adults Age 18+; Feb 16,17,19, 2011; MoE +/- 3.1%
Public (Mis)Understanding

• Semi-structured telephone interviews with 50 members of the public.

• The interviews focused on perceptions of palliative care.

• Subjects believed palliative care is about:
  • caring for people who are dying
  • maintaining comfort in the last days of life

Palliative Care

- What It Is...
- Who It’s For...
- Why You Want It....
- When to Get It...
- How to Get It...
What It Is...
The Current Definition

Palliative care is specialized medical care for people with serious illness. This type of care is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness - whatever the diagnosis.

The goal is to improve 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.

https://www.capc.org/about/palliative-care/
Put More Simply...

Palliative Care is:

- An extra layer of support
- Care focused on improving quality of life for people with serious illness
Palliative Care is a Bridge

https://www.youtube.com/watch?v=lDHhg76tMHc
Core Elements of Palliative/Supportive Care

- Symptom management
- Focus on communication
- Comprehensive care
  - Bio-psycho-social-spiritual
  - Family and caregivers
- Team-based
- Continuity over time
Which Healthcare Professionals provide Palliative care?

Social workers, psychologists, physio and occupational therapists, psychiatrists, volunteer staff

Blogs.webmed.com

VanderbiltUniversity.edu
(Most) patients with serious illness want...

- Relief of symptoms
- Communication about illness, treatment, and help with making decisions
- Support: emotional, psychological, spiritual, practical

Singer et al. *JAMA* 1999;281:163-8
Once people know...

► >92% say:

► It is important
► Patients with serious illness and their families should be educated about role of palliative care
► They are likely to consider palliative care for a loved one
Who It’s For…

- Patients with serious illness
  - Heart disease
  - Cancer
  - Chronic lung diseases
  - Stroke
  - Dementia
  - Kidney failure
  - Liver failure
- All ages
- All stages of serious illness
- All settings: home, office, hospital

National Center for Health Statistics, 2011
www.cdc.gov/nchs/data/nvsr/nvsr59/nvsr59_04.pdf
Why You Want It...
Proven Benefits

1. Improved patient and family satisfaction
2. Reduction in symptom burden
3. Prolonged life (hospice, outpatient)
4. Improved value/Reduced costs

Cancer clinic at an academic medical center

151 patients with newly diagnosed metastatic non-small cell lung cancer

All patients received standard oncology care

Half of patients randomized to receive simultaneous, outpatient palliative care from the time of diagnosis

Temel et al, NEJM 2010;363:733-42
Patients randomized to receive early palliative care:

- Better quality of life
- Improved symptoms: pain, dyspnea, nausea
- Less depression
- Less aggressive end-of-life care
- Longer life by 2.7 mo on average (11.6 v. 8.9)

Temel et al, *NEJM* 2010;363:733-42
Early Outpatient Palliative Care improved QOL

- A cluster Randomized Clinical Trial
- 24 cancer clinics in Toronto
- 461 pts with advanced cancer, prognosis of 6-24 mos
- Usual care vs. addition of monthly PC
- At 4 mos,
  - improved QOL,
  - increased satisfaction,
  - Improved symptom severity,
  - spiritual well-being

Zimmermann, The Lancet, February 19, 2014
When To Get It...
ASCO Statement

“Combined standard oncology care and palliative care should be considered early in the course of illness for any patient with metastatic cancer and/or high symptom burden.”
Early intervention for patients and families with brain tumors

- Want to have the opportunity for discussion before cognitive changes occur
- Caregivers often take over many roles, and it is helpful to be able to share the changes
- Early support to prevent isolation
Role of Hospice Care

- All hospice is palliative care, but not all palliative care is hospice
- A service for people nearing the end of life
  - Requires physician to confirm a 6-month prognosis if the disease were to take its anticipated course
- 24/7 access to palliative care experts
- Can be done at home, in a facility, or a residential hospice
Where To Get It...
Doctors and nurses provide care in the clinic in addition to the treatment.

Palliative care doctors hold clinic hours in oncology offices to see all patients with symptoms.

Palliative care in the hospital

Palliative care outpatient referral

Local doctors and nurses provide Palliative care

Cancer Society staff provide care
Brain Tumor Considerations in Palliative/Supportive Care
Special supportive needs of brain tumor patients and caregivers

- Early communication about goals and decision making. Values, who they are. What they like.
- Alert to common brain tumor symptoms that may change throughout the journey
  - Provide interventions
- Being aware of caregiver burden, strain and stress
Comparing Brain Tumor Caregivers to other Cancer Caregivers

- Higher levels or caregiver strain
- Lower levels of mental well-being
- Lower levels of physical well-being
- Higher level of ADL workload

Aoun, Daas, Howting, Lee, 2015 PlosOne, 10(12)
End of Life, Brain Tumor

- Specific symptoms throughout journey and at end of life
  - Fatigue
  - Drowsiness - Delirium
  - Headaches - Difficulty swallowing
  - Focal Neurological Symptoms - Seizures
  - Cognitive, Behavioral Changes

- Use of Steroids
- Provide nursing care
- Respect the values of the patient and their caregivers

End of Life Care for Brain Tumor Patients, UCSF
Palliative Care Manuals


http://www.cancer.net/sites/cancer.net/files/palliative_care.pdf
Living with a Brain Tumor
Thoughts and questions?