PALLIATIVE CARE

END OF LIFE CARE FOR BRAIN CANCER
OBJECTIVES

• Understand palliative care and role it plays in brain cancer
• Understand hospice and appropriate timing of referral
• Understand brain cancer end of life symptom management
Palliative Care is specialized care for patients with a serious life limiting illness. It focuses on relief of symptoms and stress, including spiritual and psychosocial issues, related to terminal illness. It realizes that medical care alone may not be most important to a good QOL as we approach death.

- It is not only “brink of death care”.
- Palliative care is broader than hospice and can be done alone with routine cancer care.
- It should be integrated into care of advanced illness and not after “all possible treatment options are exhausted”.
**Palliative Care**

- **Holistic Approach**
  - Care of the body, mind & spirit: Focusing on social, emotional, cultural, spiritual & intellectual or knowledge aspects of care supported by an interdisciplinary team and training.

- **Quality of Life**
  - Patient-centred care incorporating respect for patients’ values and preferences, provides information in clear and understandable terms, promotes autonomy in decision-making and attends to the need for physical comfort and emotional support.

- **Life-threatening & life-limiting illness**
  - Life-threatening illness is an illness which could cause a patient to die (cancer, AIDS, old age, MND, terminal diabetes or heart disease) and life-limiting includes conditions which may compromise quality of life (spastic children, metabolic disorders, severe CVA).

- **Patients & families**
  - Patients referred to DPH have an expectation of dying, therefore care of the families is included in the care i.e. Care of the infected and affected by the team while the patient is alive and into the bereavement period.

- **Identification, impeccable assessment & treatment of symptoms**
  - **Identification**: knowledge & recognition of symptoms; **Impeccable Assessment**: knowledge based professional evaluation; **Treatment**: Medication management, specialist referral, holistic intervention by Palliative Trained Team.
WHAT PATIENTS SAY THEY WANT NEAR END OF LIFE

- Pain and symptom management
- Inappropriate prolongation of dying
- Sense of control
- Relief of burden on family and caregivers
- Strengthening of relationships
6 PRINCIPLES OF PALLIATIVE CARE

- Focuses on pain and other distressing symptoms
- Affirms life and regards death as a normal process
- Intends neither to hasten or postpone death
- Integrates psychological and spiritual aspects
- Focuses on patient as well as family before and after death (bereavement)
- Believes in a team approach
- Focuses on QOL and care burdens
- Appropriate at any time in a patient with any life limiting chronic illness
- Respects patient choice, preferences and values
7 ROLE OF PALLIATIVE CARE

• Discuss goals and options
• Help with pain and other symptoms
• Encourage completion of advance care plans
• Consultative only
• Explain hospice
• Realistic prognostication and recognition of the dying process
• Concurrent with Oncology Care
WHICH PATIENTS NEED IT?

- Would you be surprised if patient died within next 12 months?
- Metastatic or locally advanced cancer—or when disease progresses
- Any newly diagnosed primary or metastatic brain tumor——
- ECOG 3 or worse
- Cancer cachexia
- Uncontrolled pain or symptoms
- Family distress—e.g. disagreement about treatment options
- Hospice discussion—early not later—3 to 6 months before death is best
- Major comorbid conditions
- Communication issues, clarification of goals or patient /family request
INDICATORS OF OVERLY AGGRESSIVE CANCER CARE

- ER visit, hospital admission or ICU stay last 30 days of life
- Chemo last 2 weeks of life—11% cancer patients receive chemo last 2 weeks of life (JAMA 1/2016)
- Absent or late Hospice referrals
• Alignment of care with goals has many benefits

• Focusing on disease control only leads to more pain, more anxiety, more family exhaustion as well as more non beneficial care and more hospitalization and they do not live longer

• The view that Palliative Care is only appropriate after all possible disease modifying therapy, which is prevalent among the medical community and public, is harmful and incorrect

• Clarification of goals of care requires realistic prognostication, recognition of the dying process and communication skills as well as time
PROGNOSIS

• Recognition of the dying process is the single most important key to good end of life care—including patient, family and physician

• Functional and nutritional status continue to be the best predictors

• Uncertainty about exact timing of death should always be emphasized but should not limit communication about dying

• Understanding the process will change decisions and help clarify goals
DISEASE TRAJECTORIES

PREDICTING PROGNOSIS

Figure 5. Trajectories of eventually fatal chronic illnesses. Source: Lynn and Adamson 2002.
# Palliative Performance Scale (PPSv2) version 2

<table>
<thead>
<tr>
<th>PPS Level</th>
<th>Ambulation</th>
<th>Activity &amp; Evidence of Disease</th>
<th>Self-Care</th>
<th>Intake</th>
<th>Conscious Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>100%</td>
<td>Full</td>
<td>Normal activity &amp; work</td>
<td>Full</td>
<td>Normal</td>
<td>Full</td>
</tr>
<tr>
<td>90%</td>
<td>Full</td>
<td>Normal activity &amp; work</td>
<td>Full</td>
<td>Normal</td>
<td>Full</td>
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<tr>
<td>80%</td>
<td>Full</td>
<td>Normal activity with Effort</td>
<td>Full</td>
<td>Normal or reduced</td>
<td>Full</td>
</tr>
<tr>
<td>70%</td>
<td>Reduced</td>
<td>Unable Normal Job/Work</td>
<td>Full</td>
<td>Normal or reduced</td>
<td>Full</td>
</tr>
<tr>
<td>60%</td>
<td>Reduced</td>
<td>Unable hobby/house work</td>
<td>Occasional assistance necessary</td>
<td>Normal or reduced</td>
<td>Full or Confusion</td>
</tr>
<tr>
<td>50%</td>
<td>Mainly Sit/Lie</td>
<td>Unable to do any work Extensive disease</td>
<td>Considerable assistance required</td>
<td>Normal or reduced</td>
<td>Full or Confusion</td>
</tr>
<tr>
<td>40%</td>
<td>Mainly in Bed</td>
<td>Unable to do most activity Extensive disease</td>
<td>Mainly assistance</td>
<td>Normal or reduced</td>
<td>Full or Drowsy +/- Confusion</td>
</tr>
<tr>
<td>30%</td>
<td>Totally Bed Bound</td>
<td>Unable to do any activity Extensive disease</td>
<td>Total Care</td>
<td>Normal or reduced</td>
<td>Full or Drowsy +/- Confusion</td>
</tr>
<tr>
<td>20%</td>
<td>Totally Bed Bound</td>
<td>Unable to do any activity Extensive disease</td>
<td>Total Care</td>
<td>Minimal to sips</td>
<td>Full or Drowsy +/- Confusion</td>
</tr>
<tr>
<td>10%</td>
<td>Totally Bed Bound</td>
<td>Unable to do any activity Extensive disease</td>
<td>Total Care</td>
<td>Mouth care only</td>
<td>Drowsy or Coma +/- Confusion</td>
</tr>
<tr>
<td>0%</td>
<td>Death</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
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</table>
• Understanding and coping with a terminal cancer diagnosis is not a one-time conversation.
• Discussion about prognosis and goals are best done separate from discussions about treatment options.
• Conversations should include family and are time intensive.
• Techniques including “ask, tell, ask” and “I wish, I worry” should be employed.
• Communication skills are essential and can be acquired.
IMPORTANT QUESTIONS—WHEN DISEASE PROGRESSES

• Do you have a living will?
• What does it say about CPR?
• Who do you want to make medical decisions if you cannot?
• Have you discussed Hospice yet?
• Are there family or spiritual issues to resolve or consider?
• Have you thought about where you want to die?
• If you thought you had only a few weeks or a few months to live, how would you spend that time? Where would you want to spend that time?
BURDENS OF CARE

- Pill burden
- Testing burden
- Treatment burden
- Transitions of care burden
- Decision burden
- Symptom burden
- Caregiver burden
- All medical decisions include benefit versus burden
PALLIATIVE CARE MODELS

Old

Life-prolonging care

Medicare hospice benefit

New

Diagnosis

Life-prolonging care

Palliative care

Hospice care

Death

Bereavement

Source: Center to Advance Palliative Care
HOSPICE

- Daily fee all inclusive program
- Prognosis 6 months or less—no limit to benefit
- Benefit periods
- 85% MHB—1982
- Tremendous growth—over 5,000 agencies and 40% all Medicare deaths
- Think of Hospice as a special insurance program for the terminally ill
- Hospice is not a place but a philosophy of care
- Each Hospice agency can decide for itself what it will and will not cover if it is related to primary hospice diagnosis
HOSPICE—LEVELS OF CARE

- Routine
- Respite
- Continuous
- General inpatient
CRITERIA FOR GIP LEVEL HOSPICE

• Only 1-2% total hospice days
• Requires unmanaged symptoms
• Patient cannot be managed in another setting
• Complex wound care
• Caregiver breakdown or actively dying patients do not qualify
• Best example would be patient with uncontrolled pain who needs pain pump or maybe rotation to another opioid before transitioning to home hospice
HOSPICE PAYMENT

• Per diem rate depending on level of care
• First 60 days of routine home care is paid at a higher rate, drops on day 61
• SIA---service intensity add on payment last 7 days of life—includes social services or RN
• Coinsurance may be charged for drugs, biologicals or respite stays---most hospices wave these
• Medicare part A—physician services can be billed unless physician works directly for hospice
• Room and board is not covered except short inpatient stays arranged by hospice
• ER, inpatient care, outpatient care or ambulance services related to terminal condition are not covered unless arranged by hospice(e.g. XRT)
HOSPICE—WHEN TO HAVE DISCUSSION

- Early is better __target when patient has 6 months or less____never too early
- Predicting 6 months or less is not that difficult____decline performance status, weight loss/ anorexia, decrease level of consciousness or progressive/recurrent CNS disease
- Oncologists tend to overestimate survival by a factor of 5(BMJ 320:469-472)
- Average patient with cancer lives only 8 days on Hospice
- Early hospice can avoid non beneficial hospital or ER visits in end of life phase(last 4 weeks)
ADVANTAGES OF EARLY HOSPICE DISCUSSION

• Brings Hospice into the picture as part of best practice-endorsed by ASCO for over 15 years
• Tells patient and family that care will be provided when needed i.e. avoids the “nothing more we can do” syndrome
• Reinforces to patient and family that they have a terminal illness, so they can plan for the future and eventual death
• It moves the anguish of facing a terminal illness upstream, when families and patients are not in extremis
• Finally, Hospice information and Palliative Care work together to prepare patient for hospice
• Hospice LOS increases with early hospice discussion
• Hospice should be 30 days or more, not 3 days
"What fits your busy schedule better, exercising one hour a day or being dead 24 hours a day?"
BRAIN CANCER MAJOR SYMPTOMS—END OF LIFE PHASE

• Drowsiness/progressive loss of consciousness—87%—most last week of life
• Dysphagia—71%—commonly associated with decreased mental status
• Motor deficits, aphasia, coordination problems—52%
• Seizures—45% late near end of life—much more common if previous seizures—only 11% had seizures if no previous history near active phase
• Incontinence—40%—before bedridden
• Cognitive decline, headache and fatigue all occurred about 1/3 of patients
• Generalized pain—25%—prevalence for all cancer 60-80%
• Nausea—20%

• Neuro Onc Nov 2010 Vol 12 issue 11
ADVANCE DIRECTIVES

• Everyone should complete—particularly important for those with chronic or terminal illness---and brain cancer----loss of cognition

• 30% or less have done so

• Attempts to provide direction to future medical decisions

• High profile cases fueled growth and development

• Benefits include generally less aggressive care near end of life, increased use of hospice and longer length of stays and less complicated grief for family

• Conversation with and appointment of health care agent or surrogate are most important

• Should be done early with brain cancer
ADVANCE DIRECTIVE RESOURCES/BILLING

- TN state form
- POLST form—only official DNR
- Five Wishes
- Conversation Project
- 99497 and 99498—first and second 30 minutes of time—billing codes
- Can be billed by any specialty in any setting (in patient or outpatient)—deductibles and coinsurance applies when done outside annual wellness visit
ETHICAL PRINCIPLES

- Patient autonomy
- Beneficence
- Maleficence—"do no harm"
- Principle of “double effect”
- “Rule of rescue”
SYMPTOM PREVALENCE—ACTIVE DYING PHASE

- Drowsiness/increased sleep—85%
- Dysphagia—85%
- Headache—36%
- Seizures—36%
- Agitation and delirium—15%
- Agonal breathing—12%
STEROIDS

When to stop? Almost always when patient cannot swallow.
Timing? Give dose early and mid day—avoid late day doses
Trial of tapering frequently or after major treatment i.e. surgery of XRT
Explain to family that steroids will not work at some point and decline likely due to disease
SEIZURES

Common presenting symptom and in about 50% in end of life phase

Usually continue AED as long as can swallow

Usually less of an issue in active phase of dying—about 1/3

Almost never use prophylactically if no history of seizures

Lorazepam SL scheduled usually works well when patient can no longer swallow

Many AED drugs can be given rectally—diazepam and phenobarb supp can be used—lorazepam can be given SQ if no IV access
DELIRIUM

• Very common with most patients in late dying phase
• Most distressing to families
• Always think about causes, some of which may be reversible i.e. urinary retention, fecal impaction or unrecognized pain
• Low dose anti psychotics sometimes with lorazepam are most often used
• Haloperidol can be given SL and SQ—go to drug for nausea on Hospice also
• Most common cause of need for GIP hospice in all cancers---less so with brain cancer
ARTIFICIAL NUTRITION/HYDRATION

- Emotional issue for many patients and families
- Religion and cultural background are important
- Nutrition and hydration become less important as we approach death
- IV fluids do not promote comfort near end of life
- Tube feedings do not prevent aspiration or improve survival in any advanced cancer
- Comfort feedings as long as patient is awake are always considered and offered
PAIN AND DYSPNEA

• Pain is not prevalent in brain cancer
• Usual and still best treatment is Morphine---many ways to administer
• Morphine SL concentrate used commonly in active phase based on appearance of non verbal signs of pain or distress
• Morphine continuous infusions can be done SQ—usually no need for IV access
COMFORT CARE

- Often provided in hospital setting when goals are comfort only
- All blood draws and ancillary services are stopped
- IVF and any IV drugs are also usually discontinued---refractory seizures may be exception
- Comfort care is meant for only very short stays days or less when out of hospital options are limited
- Inpatient hospice---GIP level---is now rarely done due to CMS limits on how it is defined and paid
RISK FACTORS/COMPLICATED DEATH

• Younger age
• Chronic Pain
• History of psychiatric diagnosis—bipolar/schizophrenia
• History of drug or alcohol misuse
• Anticipation of risk factors may help prepare better for these situations
Terminal/Palliative Sedation

- Administered when other palliative treatments are ineffective
- Basically renders patient unconscious till death occurs
- Goals of care must be very clear and everyone needs to understand intent is not to hasten death---but to relieve intractable suffering
- Some consider legal alternative to assisted death
- Usually lorazepam or midazolam drips, Propofol and barbituates have been used
- Ethical principal of double effect applies
DEATH WITH DIGNITY ACT/OREGON EXPERIENCE

- 1857 received prescriptions—1179 died—0.2% all deaths—7 regained consciousness—1998 till 6/2017
- 90% cited loss of autonomy and lack of enjoyment of activities as reason
- Only 26% cited pain
- 88% were on hospice at time of request
- 5% lived more than 6 months—11% hospice nationally
SUMMARY

• Palliative care plays important role in timely transition to hospice and avoidance of unwanted care near end of life for brain cancer

• Advance care planning is particularly important early in brain cancer

• Early hospice discussion and referral is the best way to avoid hospital and ER visits near end of life

• Palliative care should be integrated/concurrent with routine brain cancer care