

## Symptom Management at the End of Life



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## Special Thanks

- Mary Lovely, RN, PhD



## Thanks!

- Mark R. Gilbert, MD
- Howard Colman, MD, PhD
- Rochelle Manning, ADN, RN
- Michelle Hammond, RN, BSN



## Special Thanks!

- Charles Cleeland, PhD
- Marlene Z. Cohen, RN, PhD, FAAN
- Chris Armstrong



## The “Real” Lessons

What Patients’ Have Taught Me  
& Want You to Know!



## The Meaning of “Palliative” and Your Approach to the Patient

- Patients with primary brain tumors (PBT) have a poor prognosis and are associated with devastating neurologic symptoms

## Where I Come From: An Overview



- Primary brain tumors occur in ~35,000 people/year in the U.S. (<2% all cancer)
- Second most common cause of cancer death in young males
- Life expectancy less than one year for GBM, average of 7 years for the "benign" astrocytoma

## The Meaning of "Palliative"

- Life expectancy is short, but may not be different than other cancers
  - ½ of cancer pts die of their disease (Wingo, et al, 1995)
  - ¼ die within 6 mths of diagnosis, 63% live only 24 months (Brescia, 1990)
  - Those with nonresponsive solid tumors –80% live less than 12 months

## Bad Seasons: The Issue of Futility in Treatment

- Why treat if the person is going to die in a short period of time?
- Definition: "A dynamic and fluid concept of critical decision making that struggles between the tension of traditional principles of practice/autonomy, best interest, doing no harm, & justice"
- Controversy: "When does the patient enter this zone of futility?"

## "End of life = Futility"



- The time when treatment risks outweigh the benefit
  - "dynamic and fluid concept of critical decision making that struggles between the tension of traditional principles of practice/autonomy, best interest, doing no harm, and justice (Brescia, 1997).
- Clarity of this point in the PBT

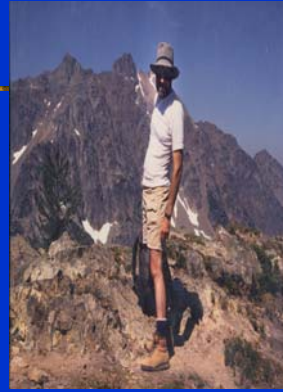
## Futility: Approach to Patients!

- Reality is what it is, not what you think that it should be!
  - Pushing your reality ("I would go on a cruise")
  - The informed patients reality should guide treatment
- Statistics are *just statistics!*
  - Novel treatments with unknown impact on survival
  - Patients can't sit and wait to die
  - Locks survival at its current level
    - learn from childhood leukemia (John Lazslo: *Into the Age of Miracles*)



## Futility: Approach to Patients!

- Educate *but don't* Dictate
- Approach to Information (*Larry Burkett*):
  - you are going to die in two months
  - There are some treatments, but they probably won't work
  - This is what I can offer you



Life is a series of lessons that must be lived to be understood or The relative nature of Providing care



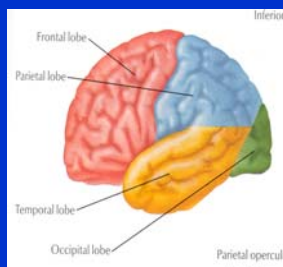
## Components of the Central Nervous System (CNS)

- Comprised of the brain and spinal cord
- Contents of the CNS
  - Blood
  - CSF
  - Tissue



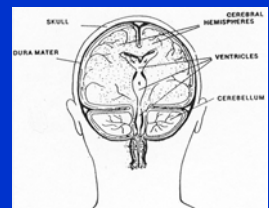
## Brain Anatomy - Tissue

- Primary cells are neurons and glia
- Significant division of the brain:
  - Cerebral Hemispheres
    - Frontal, Parietal, Temporal, Occipital Lobes
  - Cerebellum
  - Brainstem
  - Midbrain, Pons, Medulla Oblongata



## Brain Anatomy - CSF

- Lateral Ventricles
  - Choroid Plexus
- Intraventricular foramina
- III<sup>rd</sup> Ventricle
- Aqueduct of Sylvius
- IV<sup>th</sup> Ventricle
- Foramen of Magendie and Luschka
- Subarachnoid space



## Neurologic Signs and Symptoms

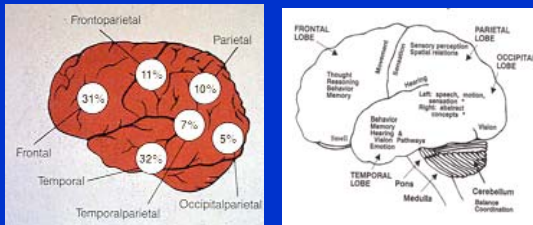
- General Neurologic Signs
  - Headache, Nausea, Vomiting
  - Papilledema
  - Mental Status Changes
  - Seizures
- Focal Neurologic Signs
  - Location Dependent



## Monro-Kellie Doctrine

- Compensatory mechanism of the brain
  - Contents of the brain have a fixed volume
  - Addition to volume → reduction in contents
- If compensatory mechanism is unable to function, Intracranial Pressure will rise

## Frequency of Brain Tumors by Location



## What We Know About Symptoms in the PBT Patient Population



## Symptoms in the PBT Patient

- Primary cited studies were performed before the use of current imaging techniques, on retrospective chart review, and reported percentage of solitary symptoms only
  - Jelsma & Bucy (1967)
    - 162 patients w/GBM from 1945-1964 reported headache, hemibody weakness, & confusion in greater than 40% of patients
  - Frankel & German (1958)
    - 219 patients with malignant gliomas from 1924-1952
    - reported headache, hemibody weakness confusion, & nausea/vomiting in greater than 40% of patients
  - Roth & Elvidge (1960)
    - 495 patients from 1928-1953
    - 38.8% reported headache for an average of 4.4 months
    - 5.2% reported generalized seizure activity for an average of 11.3 months
    - 10.1% reported hemibody weakness for an average of 5.1 months

## Symptoms in the PBT Patient

- More recent studies are also retrospective and did not report on the occurrence of multiple symptoms
  - Krouwer et al., 1997
    - 52 patients in Amsterdam with oligoastrocytomas
    - 58% with headache, 71% with seizures, 19% with weakness
  - Yeh et al., 1999
    - 65 patients with malignant gliomas between 1988 and 1996
    - Headache in 69%, hemibody weakness in 55%, all other symptoms in less than 25% of patients



## Symptoms in the PBT Patient



- Mukand and colleagues (2001) did report that 74.5% of patients reported three or more concurrent neurologic deficits and 39.2% reported five or more deficits in a group of brain tumor patients undergoing rehabilitation
  - Results with limited applicability to this review as a result of:
    - Report of neurologic deficits by clinicians, not patient report of symptoms
    - Use of patients on inpatient rehabilitation unit
    - Use of patients with brain metastases and anywhere in the course of their illness
- Meyers and colleagues evaluated cognitive deficits and neurologic signs and reported tumor location & size (and not malignancy) determined symptoms

## Limitations



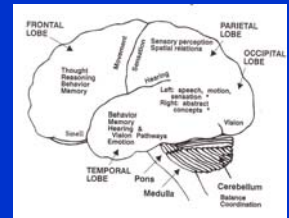
- Study limitations include:
  - Antiquity of data
  - Retrospective review
  - The occurrence of multiple symptoms not reported

## One Perspective



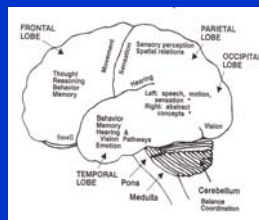
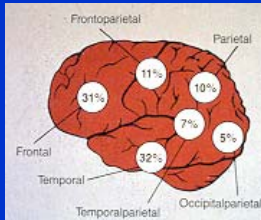
## Application to Symptoms at the End of Life:

#1: Symptoms will be neurologic and location dependent



From ABTA: A Primer of Brain Tumors

## Frequency of Brain Tumors by Location



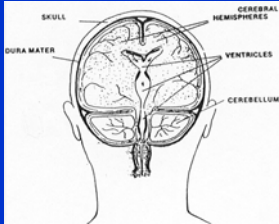
## Application to Symptoms at the End of Life:

#2: Non-neurologic symptoms will be rare

- Common symptoms of therapy are worsening of existing neurologic effects
- Treatment and complication effects may include fever, dyspnea, fatigue, etc

## Application to Symptoms at the End of Life

### #3: Death from Tumor will be 'Painless' and 'Peaceful'



*Midway  
through the  
exam, Allen  
pulls out a  
bigger brain”*

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## Specific Symptoms & Their Management

- Management of symptoms at the end of life is critical for both the patient & the caregivers!
- Consciousness & swallowing may be impaired, making medication administration difficult

## End of Life Care: Leaving a Legacy

- Symptoms at the end of life may have significant impact on the caregiver
  - “the last thing I remember is Steve seizing on the floor. He then turned blue and vomited all over himself. Why did he have to die that way?”
  - “Mama went into a coma and just lied there. She didn’t eat or drink for days. I can’t help but think she was starving”
  - “Thank God it was peaceful, like you said. It was his time. We were all there with him, at home. He would have wanted it that way.”



## Pain: The When and the How

slides courtesy of Jeffrey Weinberg, MD

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## Pain

- Pain occurs as the result of traction on the dura or blood vessels
- Primary method of pain control is the use of corticosteroids to reduce brain edema
- Should steroids be continued at the end of life?
  - Pain relief?
  - Extending the inevitable?
- Options include Fentanyl patches and Roxanol (which can be absorbed under the tongue)

## Immediate Seizure Management

- Appropriate management: Use of a structured program for seizure management reduces occurrence and impact
  - Maintain safety and prevent injury

## Seizures: medication

- Seizure risk does not decrease near the end of life
- Continuation of oral anticonvulsants may be difficult
- Phenytoin, Phenobarbital, Depakote, and Carbamazepine can be compounded into suppository form
- Ativan provides good seizure prophylaxis (pill or intensol form can be absorbed sublingually). Usual dosage is ½ to 1mg every 6 hours

CONFUSION/PERSONALITY CHANGE

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## Confusion

- Alterations in cognition and personality can occur
- Maintaining safety is the primary goal (and often the most difficult)
- Medications to manage:
  - Haloperidol
  - Risperdal
  - Antidepressants/anxiolytics

## Confusion

- It takes a village:
  - Timing or symptoms may require hospitalization
    - Change in focus before change in venue
  - Guidance regarding meeting own needs and accepting help
    - 'Shift work' to allow for sleep
    - The important of 'self time' during 'illness time'

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## Question Reality!

The informed patients  
reality  
should be the  
guide

The End!