

## End of Life Issues of Primary and Metastatic Brain Tumor Patients

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## Caregivers and End of Life

- Nature of caregiving in brain tumor patients at end of life
- Caregiving and specific problems related to brain tumor patients
- Anticipating the end of life events
- Nursing actions to help the caregivers
- Two end of life scenarios

## Why are Caregivers so important at the end of life?

- Patients require more care
- Financial resources may be diminished
- Shorter hospitalizations
- Less reimbursable home care

## Positive Aspects of Caregiving

- Feel honored
- Sense of accomplishment
- Better relationship with family
- Provides personal growth



Archbold, 1995; Nijboer, 1999

## Negative Aspect of Caregiving

- Increased plasma norepinephrine
- Poor antibody response
- Exhaustion
- Decreased physical health
- Social isolation
- Lower income causes more distress

Bucher, 2000; Given, 1996; Schumacher, 2000;

## Caregiver Depression and Burden at End of Life

- 152 caregivers followed with patients
  - High level of depression with low levels of reported demands of care
- Spouses
  - Less depression with employment
- Adult children
  - More lifestyle adjustment, multiple demands
  - Increased depression with earlier death
  - More depression with employment



Given, 2004

## Brain Tumor Patients at End of Life A Dual Challenge

- Neurological Issues
- Cancer Issues

## Neurological Issues

- Cognitive issues
    - Memory loss
    - Judgment difficulties
    - Visual spatial disorders
- RESULTS IN
- Loss of the person as was once known
  - Grief often experienced twice
  - Significant role changes

## Neurological Issues

- Neuropsychiatric Disorders
    - Behavior changes
    - Delirium, hallucination
    - Change in affect
- RESULTS IN
- Fear of unpredictable behavior
  - Social isolation

MOST DIFFICULT ISSUE TO MANAGE

Sherwood, 2004

## Neurological Issues

- Impaired Physical Function
    - Decreased mobility
    - Unable to do ADLs
- RESULTS IN
- Exhaustion
  - Decreased physical health



## Cancer Related Issues

- Dying from an incurable disease
  - Stress and depression from the end of life process
  - Have I done all the I could have?
- Effects of tumor and treatment
  - Neurological effects due to treatment
  - Effects of dexamethazone and other drugs

## What Caregivers Want to Know

- How to communicate effectively with the health care professionals
- What the care recipient may experience physically and emotionally
- How the caregiver can best support the recipient at end of life

NCI, 2003

## Anticipation of End of Life Events

- Explain neurological deterioration
  - Glioblastoma vs. astrocytoma
- Explain protection against seizures
- Discuss pain management options
- Discuss the importance of nursing care
- Explain the dying process

## Methods to Support the Caregiver during End of Life

- Family care or respite services
- Communicate with other caregivers on list serves
- Keep in touch with medical services
- Hospice when ready
- Plan for the future needs – Caregiver training

## NBTF Caregiver Training Program

- Anatomy and Physiology
- Symptom Management
- Neuropsychology
- Body Mechanics
- Legal information
- Hospice and End of Life

[www.brainumor.org](http://www.brainumor.org)

## After the End of Life

- Excerpts from Stella: Fighting for Life Against a Malignant Tumor
- Excerpts from A Mother's Perspective: A Poetic Journal

