



Memorial Sloan Kettering  
Cancer Center

## **Family Caregiver Burden and Unmet Needs:**

# **What is Uniquely Different in Caregiving for Individuals with a Primary Brain Tumor?**

Wednesday, May 30<sup>th</sup>, 2018

Janine Genovese, LCSW, OSW-C and Dawn Kilkenny, LCSW-R, ACHP-SW



# Objectives of the Talk

- Become familiar with the impact of caring for a patient diagnosed with a brain tumor
- Understand how caregivers often cope with the rapid functional and neurological decline of their loved ones
- Explore options for psycho-educational support for the caregiver throughout the disease continuum
- Illuminate positive effects of a palliative care approach on the caregiver



# Significant Prognosis Statistics



- The median survival rate for glioblastoma in 2008 was less than one year.\*
- The current median survival is about 14.6 months with standard treatment of surgery, radiation and chemotherapy.\*\*

\*Walid, 2008

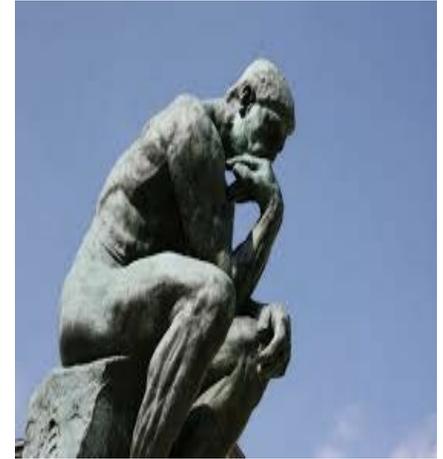
\*\*American Brain Tumor Association



Memorial Sloan Kettering  
Cancer Center

# Neuro-Psych Symptoms

- Personality and Behavior
  - loss of emotional control, indifference and change in behavior
- Psychological Distress and Mood Issues
  - mania, feelings of anxiety, depression
- Hallucinations and Psychosis
  - visual and auditory hallucinations are rare and psychosis may fluctuate\*



\*Boele, et al., 2015



# Cognitive Deficits



- Attention
- Memory
- Executive functioning
- Information processing
- Expressive aphasia



# What is the Impact on the Caregiver?

- Experienced a loss of equality (spousal relationships)\*
- Viewed disabilities of the body as easier to manage than disabilities of the mind\*
- Disappointed by the team's inability to discuss death and dying\*\*
- Reluctant to use their loved one's appointment time for their own needs\*\*\*
- Perceived need for early information\*\*\*\*

\*Ford et al., 2012, \*\* Moore, et al., 2013, \*\*\*Arber et al., 2013 and Bakitas et al., 2017, \*\*\*\*Arber et al., 2013 and Ownsworth et al., 2009



# Caring for Rapid Decline of Patient: Caregiver Sleep Loss



Sleep disruption  
and deprivation  
results in the  
following changes



## Physical

- Changes in immune, metabolic or endocrine function
- Increase in blood pressure

## Cognitive

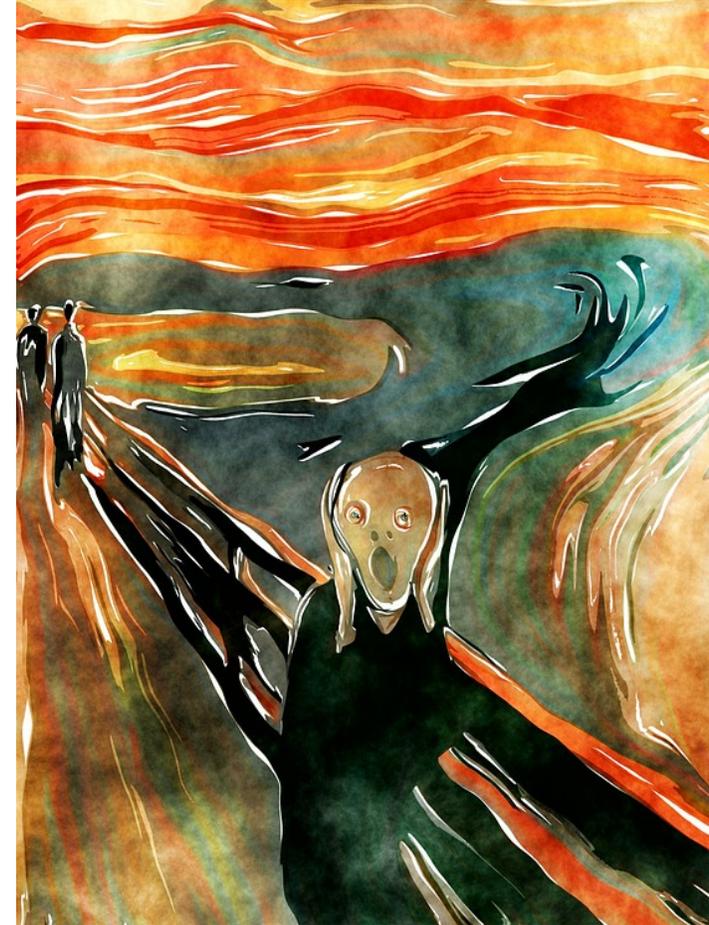
- Short term memory loss
- Poor problem-solving
- Increase in accidents
- Errors in judgment

## Emotional

- Mood fluctuations
- Decreased motivation
- Changes in social interactions with family, colleagues and friends

# Simon's Story

- 60 y/o M with new glioblastoma
- Abrupt changes in cognition and personality
  - irritable, unable to think logically or be redirected
  - impulsive
  - loss of control
  - anger
  - unaware of his impairments



# Simon's Story: The Caregiver Experience



- Interpersonal relationship issues
- Fear and anxiety
- Anticipatory grief



# A Palliative Care Approach for Supportive Care Needs



- The National Institute for Health and Clinical Excellence (NICE, 2006) “guidelines recognized that for patients with a primary brain tumor a palliative approach may be needed from the time of diagnosis.”\*
- Research evidence recognized difficulties in identifying patient’s needs (as unique) at the end of life and recommended that training programs for the generalist palliative care - healthcare professional are needed.

\*Ford et al., 2012, p.398



# Palliative Care for Persons with a Primary Brain Tumor

- Sudden transition to permanent cognitive and physical deficits makes doctor-patient communication highly unlikely.\*
- Gradual decline of cognitive physical deficits suggests that Advanced Care Planning be discussed early on for improved quality of life.\*\*
- Robust studies on this topic are suggested to include study design, outcome measures, and defined interventions to inform policy and practice.\*\*\*

\*Halkett, et al. 2010, \*\*Walbert and Chasteen, 2015, \*\*\*Song et al., 2016.



# Incorporating a Palliative Care Approach into Oncology Team Practice

Recommends using the TEAM-Based (Time, Education, Assessment, and Management) Palliative Care approach which highlights using standardized assessment tools for repeated, structured visits throughout the disease continuum.

## *Foundational Questions for a Palliative Care Approach:*

How do you like to get medical information?  
What is your understanding of your situation?  
What is important to you?  
What are you hoping for?  
Have you thought about a time when you could be sicker?



# Supporting the Caregiver: The Social Work Role in Palliative Care

- Facilitate advanced care planning
- Advocate on behalf of the patient and family
- Lead education workshops
- Coordinate psycho-educational support groups
- Mediate conflicts within families, including with the interdisciplinary team
- Provide counseling and psychotherapy for individuals, couples and families
- Intervene in Crisis

Watts, 2013



# Program Supports for the Caregiver

- MSK volunteer caregiver to caregiver mentorship program
- MSK caregiver support groups
- Community or national resources



# Benefits of Social Work Collaboration



- Caregiver: Seamless support of key areas of need
- Team: improves communication flow of interdisciplinary team
- Collegial Social Work: improves feelings of isolation, helplessness and burnout



# Enriching Team Communication

## Psychosocial Care Team (PCT)

- Co-facilitate monthly interdisciplinary care rounds with psychiatry
- Prepare case discussions and create monthly minutes
- Discuss complex cases and how to best meet the needs of the service

## Neuro-Oncology Palliative Care Rounds

- Co-facilitate monthly care rounds with neuro-oncologist
- Provide research article(s) to the service for suggested reading
- Explore unique medical, ethical, or practical challenges of caring for persons with brain tumors and their caregivers



# Future Plan for Program Development



Review current questionnaires for future use or create a new questionnaire for caregivers of people with brain tumors to complete that highlights their needs early on.



# Conclusion

- Caregivers of persons with brain tumors do not feel adequately prepared for caregiver tasks.
- There is a greater need for prognostic information earlier in the care continuum.
- Palliative care can be used as a formal approach within the Oncology team's practice.
- Social work plays a key role in facilitating communication, psycho-education, and advanced care planning for people with primary brain tumors and their caregivers.



# Questions, Comments, Feedback



Janine Genovese, LCSW, OSW-C

[genovesj@mskcc.org](mailto:genovesj@mskcc.org) (848-225-6332)

Dawn Kilkenny, LCSW-R, ACHP-SW

[kilkennd@mskccc.org](mailto:kilkennd@mskccc.org) (646-888-8112)

