Family Caregiver Burden and Unmet Needs:
What is Uniquely Different in Caregiving for Individuals with a Primary Brain Tumor?

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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
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:

<table>
<thead>
<tr>
<th>Physical</th>
<th>Cognitive</th>
<th>Emotional</th>
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<tr>
<td>• Changes in immune, metabolic or endocrine function</td>
<td>• Short term memory loss</td>
<td>• Mood fluctuations</td>
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<td>• Increase in blood pressure</td>
<td>• Poor problem-solving</td>
<td>• Decreased motivation</td>
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<td>• Increase in accidents</td>
<td>• Changes in social interactions with family, colleagues and friends</td>
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<td>• Errors in judgment</td>
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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?

Bakitas et al., 2017
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

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