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Cancer Center

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.**

*Valid, 2008

**American Brain Tumor Association



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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



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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



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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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