The Changing Care Needs for Patients and Caregivers Throughout the Brain Tumor Journey

MARY P. LOVELY, PHD, RN, CNRN
ASSISTANT ADJUNCT PROFESSOR
UNIVERSITY OF CALIFORNIA SAN FRANCISCO
PATIENT ADVOCATE CONSULTANT
Thank you to the Brain Tumour Alliance Australia for funding my trip to Australia and Cancer Society in New Zealand.
Brain Tumour Time Frames

- Initial Diagnosis
- Time after first treatment
- End of life
Post Diagnosis Needs

Patient and caregiver needs from diagnosis to treatment

- Diagnosis Clarification (molecular)
- Specific treatment information
- Anticipate and recognize tumor symptoms and treatment side effects
- Communicate and develop relationships with healthcare professionals

Realizing Questions:
- What can I control?
- Where can I find and get support?
The 2016 World Health Organization Classification of Tumors of the Central Nervous System: a summary

David N. Louis¹ · Arie Perry² · Guido Reifenberger³,4 · Andreas von Deimling⁴,5 · Dominique Figarella-Branger⁶ · Webster K. Cavenee⁷ · Hiroko Ohgaki⁸ · Otmar D. Wiestler⁹ · Paul Kleihues¹⁰ · David W. Ellison¹¹
WHO Classification

Glioma Classification

Phenotypic data (Tumor type) and genotypic data used

Common genotypic data used in the new revisions:

1. **1p 19q** co-deleted or non co-deleted
2. **IDH status**  Mutation or Wildtype
How do we realistically use this classification?

• Prognostic data
  • IDH mutation
  • IDH wildtype

• Required information for clinical trials

• Clinical implications for 1p19q deletion and codeletion.

• Glioblastoma patients will still be treated the same whether or not they have the mutation at the moment. (Dr. Hovey)
Patient-centered care

Patient/Family Navigator
- Assesses needs and ability to understand care plans
- Provides Educational Resources
- Listens
- Provides support
- Trust
- Identifies barriers for treatment and Quality of Life
- Work together throughout disease stages
- Facilitates discussion with healthcare team

Healthcare Professional
- Advisor
- Navigator
- Coordinator
- Doctor

“Care and cure”
Assessing Symptoms

Symptom identification in 651 patients over five studies using the MDASI-BT

Fatigue
Drowsiness
Difficulty remembering
Disturbed sleep
Distress

Challenges of Taking Oral Medications

- Chemotherapy, steroids, anti-epileptic medications and others
- Medication Management
  - Oral vs Intravenous
- Cognitive deficits
- Statements from caregivers
- Assessment of ability to take medications
Post Initial Treatment Phase

Change

Loss

A New Reality

Lovely et al. (2013), Onc Nurs. Forum 40(3) 267-274.
Potential Role and Relationship Challenges

Roles reversed or assumed by caregiver

Survivors not entrusted with responsibilities

Relationship changes: intimacy

Loss of parenting dynamic,
  • being overruled or left out

Children take on premature caregiver role
Patient’s Loss of Independence and Spontaneity

“I miss being able to go off and do things by myself.”

• Loss of a drivers license
• Getting lost
  • Visual/Spacial
• Activities planned carefully or abandoned
A New Reality: Taking Back Control

- Acknowledge the change
- Set new priorities
- Slow down
- Change expectations
- Take one day at a time
- Make healthy choices
“I need to find my people!”

- In person support groups
- Attending patient and family conferences
- Pets
- Spiritual guidance
- Healthcare professionals
Online Supports & Social Media

ABTA: Online support topics
Mentorships

BTAA: helpline, resources
Australian Cancer Council

New Zealand Support Services?
Unique Support Models

Milton Marks Family Camp

Newsletters and Publications

Networking
Serially assess neurological deficits

Assess and identify neurological deficits
- Declining physical movement
- Slowing of activities
- Vision

Adequate sleep

Nutrition and Exercise

Caregiver Specific Challenges

Several studies report:

- 40-48% report **anxiety** and **depression**
- 72-86% report high levels of **stress**
- Different stress than patients: **radical role shifts**.
- **Neurobehavioral changes** are difficult for caregivers to handle.

Ford et al. (2012) Neurooncology 14(4);392-404
Comparing Brain Tumor Caregivers to other Cancer Caregivers

322 caregivers of cancer patients, 29 brain tumor caregivers

Family Appraisal of Caregiving Questionnaire

Results: Comparing caregivers of patients of all other cancers

- Higher levels or caregiver strain \( (p = 0.011) \)
- Lower levels of mental well-being \( (p = 0.010) \)
- Lower levels of physical well-being \( (p = 0.009) \)
- Higher level of ADL workload \( (p = 0.039) \)

Aoun, Daas, Howting, Lee, 2015
PlosOne, 10(12)
Some Caregivers Develop Systemic Inflammation

108 brain tumor caregivers followed from time of dx, 4, 8, 12 months
Longitudinal profile of inflammatory cytokines (IL – 6 and IL 1ra)

<table>
<thead>
<tr>
<th>Specific groups who were burdened with disrupted schedules</th>
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<tbody>
<tr>
<td>High IL-1ra</td>
<td>Male Caregivers with anxiety</td>
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<td>Obese caregivers</td>
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<td>Less likely high IL-1ra</td>
<td>Caregivers with healthy weight</td>
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<tr>
<td>High IL-6</td>
<td>Caregivers under 30 years</td>
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ABTA Caregiver Online Resource

http://www.abta.org/brain-tumor-treatment/caregivers/
Palliative Care is specialized care for people with serious and/or life threatening illnesses. Palliative care focuses on providing patients with relief from the symptoms, pain, and stress of a serious illness. The Goal of Palliative Care is to **improve quality of life for both the patient and their family**.

Palliative Care is an **Extra Layer of Support**. It is appropriate **at any age and at any stage in the disease**.

https://www.capc.org/about/palliative-care/
“Combined standard oncology care and palliative care should be considered early in the course of illness for any patient with metastatic cancer and/or high symptom burden.” ASCO

Brook Calton MD, slide acknowledgment
Introducing Palliative Care for brain tumor patients

Early in the disease

Why:
- Maintain best quality of life
- Manage difficult symptoms
- Discuss decision making, treatment choices, goals, desires because of changing cognitive status.

Koekkoek et al., Handbook of Neurology, 2016, 315-326
Walbert et al., J Neurooncol., 117(2):217-224
End of Life

Specific symptoms at end of life
- Drowsiness
- Delirium
- Headaches
- Difficulty swallowing
- Focal Neurological Symptoms
- Seizures
- Cognitive, Behavioral Changes

Use of Steroids

Provide nursing care

Respect the values of the patient and their caregivers

End of Life Care for Brain Tumor Patients, UCSF
Palliative Care Manuals

1. Transitions in Care for Patients with Brain Tumors: Palliative and Hospice Care

2. End-of-Life Care for Brain Tumor Patients
   - Manual for Health Care Providers

3. ASCOanswers Palliative Care
   - Improving Quality of Life for Patients and Families
Providing Patient-Centered Care