Myths & Meaning During Survivorship

Joseph Greer, Ph.D.
Program Director, Center for Psychiatric Oncology & Behavioral Sciences
Massachusetts General Hospital Cancer Center
DISCLOSURES & SUPPORT

• I have no stocks, patent rights or employment with any company

• I have consulting/royalty agreements with: Vector Oncology, Springer Publishing Company
Overview

- Case Example
- Domains of Quality of Life
- Types of Core Conflicts in Survivorship
- Finding the “Middle Space” and Meaning
Case Example: “Ron”

• **Background:**
  - 68-year-old married man with two adult children and several grandchildren
  - Retired professor

• **Medical History:**
  - Diagnosed with glioblastoma
  - Completed surgery, radiation, and now taking oral chemotherapy

• **Presenting Concerns:**
  - Distress about how to manage changes in cognition and functioning
  - Worry about the effects of cancer on family
  - Anxiety about how to cope with future uncertainty: “living in limbo”
Case Example: “Living in Limbo”

- Any intermediate, indeterminate, or transitional state

- For many with brain cancer, limbo is the ongoing state of uncertainty that begins after diagnosis with respect to what the future holds and which direction to take in life

- The limbo experience may cause significant stress, and at times, symptoms of anxiety and depression
Domains of Quality of Life

- Physical
- Emotional
- Social
- Functional
- Existential
Physical

**Treatment**

Minimize or ignore symptoms and side effects

Feel like failure for reducing chemotherapy or needing to stop clinical trial

Don’t disclose side effects to care team

**Toxicity**

Perceive side effects as harmful

Misinterpret symptoms as recurrence or progression

Avoid treatment or seek a lot of reassurance from care team, internet, loved ones


When possible, try to perceive side effects as chemotherapy working to try to stop cancer

Work with care team to clarify concerns about symptoms and side effects to optimize adherence

Engage in symptom management strategies, such as relaxation techniques
Example: Relaxation Training

- Deep, Diaphragmatic Breathing
- Progressive Muscle Relaxation
- Mindfulness Meditation
“Everything is fine; I am one of the lucky ones.”

Always have to stay positive to ‘fight’ the cancer

Avoid triggers of thoughts and feelings about cancer

“I have lost all hope.”

Become anxious/depressed and consumed with negative thoughts about cancer

Disengage from meaningful life activities and relationships
“Middle Space”

- **Shutdown**
- **Overwhelm**

Acknowledge the vacillation between moments of sadness and grief along with gratitude and hope.

Consider ways that life goals may have changed and continue to engage in activities and relationships that matter to you.

Try to cultivate positive emotions.
Example: Positive Emotions

Pick a word below that calls to you and spend the next minute thinking about how your day would be different if you cultivated more of that state:

<table>
<thead>
<tr>
<th>Inspiration</th>
<th>Humor</th>
<th>Peace</th>
<th>Joy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Optimism</td>
<td>Gratitude</td>
<td>Acceptance</td>
<td>Freedom</td>
</tr>
<tr>
<td>Courage</td>
<td>Healing</td>
<td>Connection</td>
<td>Openness</td>
</tr>
<tr>
<td>Energy</td>
<td>Love</td>
<td>Hope</td>
<td>Serenity</td>
</tr>
</tbody>
</table>
Social

Breadwinner

Shield loved ones from the effects of cancer
Feel responsible to maintain same roles with family and friends as before diagnosis
Put on ‘strong’ face for others

Burden

Consider oneself as a “burden” to family and friends
Perceive that one’s identity has been reduced to being only a “cancer patient”
Feel distressed by seeking support from others
“Middle Space”

Consider perspective of how you would respond if roles were reversed

Acknowledge and affirm one’s value and identity across all life domains

Use effective communication skills to call upon people based on who best meets different support needs (informational, emotional, practical)
Example: Assertive Communication

The three “Fs” for effective communication:
- Statement of Fact
- Statement of Feeling
- Statement of Fair Request
Functional

**Overwork**
- Ignore changes in functioning or fluctuations in energy
- Try to achieve too much in one day
- Prioritize responsibilities and life tasks over self-care

**Under-exert**
- Become overwhelmed by changes in functioning and fatigue
- Withdraw from physical activity and become deconditioned
- Fall behind on responsibilities and life tasks
“Middle Space”

Overwork

Under-exert

Proactively monitor fluctuations in energy within and across days

Incorporate self-care activities in every day, not just attend to demands

Modify and pace activities to help conserve energy and to accomplish more over time
Example: Activity Pacing

**Prioritizing activities**
- Identify most important tasks
- Differentiate responsibilities from pleasurable activities

**Planning activities**
- Categorize activities in terms of physical demand
- Brainstorm ways to modify activity (duration, intensity)

**Pacing activities by time**
- Alternate between physically stressful and non-stressful activities to avoid overexertion
Existential

**Bucket List**

Have a heightened sense of urgency and meaning because of cancer diagnosis with uncertain expectations about prognosis and future

**Grocery List**

Must still attend to life’s day-to-day (and sometimes mundane) needs in which family, work, and other priorities have not changed
Recognize false dichotomy of life events as being either meaningful or mundane

Take time to be reflective about your life, accomplishments, relationships, and existential questions that matter most to you

Affirm lifelong values while incorporating new goals
Example: Finding Meaning

1. List 1 or 2 experiences when life has felt most meaningful to you.

2. Ask yourself, “who am I?” Before cancer? After cancer?

3. When looking back on your life, what are the most significant memories, relationships, traditions etc. that have impacted you?

4. What are the most meaningful roles, activities, or accomplishments that you are proud of?

5. List three ways in which you connect with life and feel most alive.

Revisit the Case of “Ron”
Summary

- Try to pull back from extreme thoughts and behaviors
- Recognize and affirm one’s full self
- Identify and cultivate what matters most to you
Thank You!

“You can’t stop the waves but you can learn to surf”

~ Jon Kabat-Zinn
Thank you for joining us for our presentation on “Insert Presentation Name”). We hope the information that you received was beneficial. This Presentation was offered by the American Brain Tumor Association, an Illinois not for profit corporation (the “Company”), at no charge to users of the World Wide Web, with the express condition that the Presentation’s attendees agree to be bound by the terms and conditions set forth herein.

The information provided from this Presentation was for informational purposes only. This Presentation: (i) was not intended as medical advice, diagnosis or treatment; (ii) was not a substitute for medical advice, diagnosis or treatment; and (iii) does not provide advice on diagnoses, treatments or conditions for individual patients. All health and treatment decisions must be made with your physician(s), utilizing your specific, confidential and individual medical information.

This Presentation may have contained sponsorships. Sponsors are solely responsible for ensuring that material submitted for inclusion in this Presentation on the Company’s website is accurate and complies with applicable laws.

A sponsor’s inclusion in this Presentation is not an endorsement or recommendation of any product, treatment, physician, hospital, test, procedure, opinion or other information that may be mentioned during this Presentation. Reliance on any information in this Presentation is solely at your own risk.

The Company, its affiliates, assigns and agents are not responsible, and expressly disclaim any liability, for errors or omissions in information provided in this Presentation or any actions resulting from the use of such information.

In addition, the references set out in this Presentation are provided for your convenience only. The Company does not endorse the information contained on linked websites or individual(s), companies or institutions operating such websites.

Please do not hesitate to contact us if you have any further questions. Thank you for being an exceptional audience.