Remembering the Quality in Quality of Life

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Psychosocial Impact
• Hematopoietic stem cell transplant recipients often experience...
  – Fatigue
  – Cognitive changes
  – Social isolation
  – Occupational disruption & financial hardship

• Those with chronic GVHD can also experience...
  – Significant physical limitations
  – Significant changes in functional status
  - Long-term morbidity & unpredictability

*Can result in deterioration of quality of life & psychological distress
• **What we know:** Chronic GVHD is an important predictor of anxiety & depression in HCT survivors (Mosher et al., 2009)

• 2018 study looked at the association between psychological distress and clinical outcomes in patients with chronic GVHD

  – 19.3% of individuals reported being moderately to extremely bothered by depression
  – 22.8% reported being moderately to extremely bothered by anxiety
  – 14.1% reported being bothered by both anxiety and depression

El-Jawahri et al., 2018
• One-fifth of those with chronic GVHD struggle with bothersome depression or anxiety symptoms
  – Other studies have shown that rates of depression are closer to 25-40%, and rates of anxiety are closer to 18% (moderate to severe range)

• Compared to those without self-reported depression...
  – Those with self-reported depression had lower quality of life, worse physical functioning, higher chronic symptom burden, and lower overall survival
    • Those with self-reported depression were less likely to be married

• Compared with patient without self-reported anxiety...
  – Those with self-reported anxiety symptoms had lower quality of life, worse physical functioning, high chronic symptom burden, but no difference in overall survival
The relationship between self-reported depression & anxiety symptoms and patient outcomes remain significant even after controlling for the severity of chronic GVHD and other transplant factors.

What does this tell us?

- Those who experience significant psychological distress are at high risk of prolonged suffering (physical, emotional, etc.)

- Supportive care interventions are *key* in addressing the needs of this vulnerable population
• How does depression lead to lower overall survival?
  – Differences in health behaviors
    • Non-adherence & poor medical follow-up
  – Increased rates of desire for hastened death & suicide
  – Psychobiological processes resulting in immune activation and elevation in proinflammatory cytokines (believed to play a role in the onset of chronic GVHD)

  – Strong evidence that depression, anxiety, posttraumatic stress disorder (PTSD), and fatigue increase activation of the immune system → *highlights the “mind-body connection”*
Prevention & Intervention
• Psychosocial transition → a major life experience that requires individuals ‘to restructure their ways of looking at the world and their plans for living in it’ (Parks, 1967)

• Can potentially result in simultaneous negative & positive outcomes for the same individual as their world view evolves to accommodate the stressful circumstances
  – Personal growth
  – Renewed relationships
  – Greater appreciation of life
• **Helpful Strategies:**

  – Avoiding attempts to avoid or rid of challenging emotions; **emotions are transient**
  
  – Engaging in compassion of your personal experience, whatever it may look like
  
  – “Flipping the Coin” & exploring alternative perspectives
  
  – Acceptance of what is outside of your control (doesn’t mean you have to like it!)
  
  – **Acting toward and committing to living a valued life**
    
    • Exploring what is truly important to you (e.g., family, independence, sense of meaning, comfort, etc.)
    
    • Are you placing your energy in the right place?
  
  – Participation in meaningful activities (e.g., hobbies, exercise, music, etc.) & self-soothing activities (e.g., mindfulness & meditation, taking a bath, and other self-care)
  
  – Being transparent about your needs (be specific) & **accepting help**
• **Support groups & other social support**
  
  - For both patients and caregivers
  - Brings people together who have gone through similar experiences & provides opportunity to establish additional social support

  • Hospital resources
  • Social media groups & community forums (BMTSupport.org)
  • National organization (Be the Match, Leukemia & Lymphoma Society, Gilda’s Club, & Imerman Angels)
• **Counseling & psychotherapy**
  – Stem cell transplant programs often have an associated behavioral health provider
  – Private practice practitioners or community mental health
  – Spiritual care
    • Can reduce anxiety and promote hope
  – Financial counseling

• **Palliative Care**
  – Relieve the suffering via the comprehensive assessment and treatment of physical, psychosocial, and spiritual symptoms patients experience
• **Pharmacological interventions**
  
  – Antidepressants
  
  – Anxiolytics
  
  – Sleep aids
  
  – Appetite stimulants

  – *If experiencing further complications/concerns, a primary care provider or psychiatrist can provide further recommendations*
• Psychological crisis services:
  – Dial “988” (National Suicide Prevention Lifeline)
  – Call local crisis line
  – Present to the nearest emergency department
Thank you!

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https://www.henryford.com/services/transplant/stem-cell
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