Coping with the Stress of Caregiving

Celebrating a Second Chance at Life Survivorship Symposium

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Coping with the Stress of Caregiving

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**Highlights**

- Cancer caregiver statistics
- Caregiver responsibilities
- Unique position of BMT Caregivers
- Emotional and mental health concerns
- Impact of COVID-19
- Distress screening for caregivers
- Signs of caregiver burnout
- Resources and coping

**Cancer Caregivers**

- 16.9 million cancer survivors (ACS & NCI 2016)
- 22.2 million by 2030
  - How many caregivers?
  - 75% of families have at least one member who is a cancer survivor
- About 23,000 stem cell transplant performed each year
- Caregivers provide:
  - 75-80% of care
  - 8.8 hours of care/day
  - >4 years of caring over course of cancer journey (Kim, 2010, Van Ryn, 2011)
What do Caregivers do?

- Provide unpaid care & health-related assistance
- Medication acquisition/dispensing
- Symptom management
- Meals/nutritional assistance
- Supervision, adherence
- Errands/bill paying
- Emotional Support
- Coordinating Care
- Communication with providers

Caregiver: An Essential Team Member

- Social support to patients is invaluable, vital
  - “Invisible” member of the medical team
- Caregivers essential for optimal treatment of their loved one
  - Ensure treatment compliance, continuity of care
- Measured distress sometimes higher in caregivers than patients
  - E.g. higher levels of caregiver anxiety than patient anxiety when cancer incurable (Jacobs et al., 2017)
BMT Caregiver

• Long-term commitment of care
  – Patient’s needs change by stage of survivorship
    • Initial diagnosis, treatment, transplant, post-transplant
  – Significant life disruption of transplant recipient and caregiver
  – Multiple roles
  – Fear and uncertainty

Little medical training pre-caregiving

• Steep learning curve
• Managing medications / dosages
• Monitoring symptoms / complex decision making
• Decreasing risk for infection
• Enforcer of rules and restrictions (“bad cop”)
• Post-transplant morbidities (e.g. GVHD)
Questions BMT Caregivers Ask

- “When do I stop being a caregiver?”
  - Survivorship needs (late effects, secondary cancer prevention)
- “I don’t know how to pull back? There was so much responsibility placed on me.”
- “How do I return to normalcy?”
- “I don’t think I’ve processed all I have been through.”
- “No one understands.”

BMT Caregiver Mental Health

- Depression
  - 3.5 x more risk for depression several years after transplant among spouses of HCT recipients (Bishop et al., 2007)
- Sleep
  - Prior to HCT caregivers report significantly higher levels of anxiety, stress and insomnia (Simineau et al., 2013; Siston et al., 2001)
- Anxiety, less social support, greater marital dissatisfaction, loneliness, less spiritual wellness than peers (Bishop, et al., 2007)
BMT Caregiver Needs

- Significant caregiver physical and emotional needs (Jim et al. 2014)
  - Social isolation
  - Struggles in knowing how much to push (hobbies, activity, exercise)
  - Closer relationship and also strain
  - Significant need in learning to cope and help patient cope
  - Formal and informal self-care can be neglected

Impact of COVID-19

- Caregivers with increased gate keeping
- Limitations on attending inpatient / outpatient visits
- Increased COVID anxiety/fears
  - Dealing with possible exposures and positive status
- Impact of pandemic
  - Less people to assist with caregiving
  - Work, finances, child care
- Support networks drastically impacted
**BMT Caregiver Distress Screening**

**The University of Kansas Cancer Center**

**Red Flags**

- Noticeable change in appearance
- Marked change in communication
- Obvious changes in behaviors
- Patient makes comments of concern
- Patient has change in complexity of need
Signs of Caregiver Burnout

- Ignoring your own health problems/symptoms
- Eating poorly
- Overusing tobacco, alcohol or other substances
- Giving up exercise
- Losing contact with friends
- Bottling up feelings of anger and frustration
- Outbursts
- Feeling resentful or unreasonably annoyed
- Feeling anxious, distressed, sad, hopeless (two weeks)
- Blaming patient
- Feeling tired all the time
- Sleeping poorly
- Trouble concentrating

Where do I start?

- www.bmtinfonet.org
- somedays is today
- BE THE MATCH
- DOMINO donors
- COTAC
- NCI
- NCI

Visit www.bmtinfonet.org
Caregiver Resources

- BMTInfoNet
  - Caring Connections Program
- Be The Match
  - https://bethematch.org/
  - One on one telephone support
  - “The Caregiver’s Companion” book
- Leukemia and Lymphoma Society
  - https://www.lls.org/support/caregiver-support
- Lotsa Helping Hands
  - https://lotsahelpinghands.com/
- Online Therapy e.g. Talkspace

Caring for the Caregiver

- Patients
  - Encourage your caregiver to take time off
  - Find small contributions to relieve feeling of burden
  - Encourage caregiver’s own outlets
  - Be open and honest, listen
  - Support their hobbies and activities that bring meaning/joy
  - Be mindful of language (“self-care”)
Caregiver Self-Care

- Sleep, eat, exercise
- Mindfulness / Relaxation practice
- Utilize supports / ask for help
- Focus on things you can control
- Celebrate small victories / silver lining
- Express feelings / schedule self-check in
- Practice radical acceptance

Skills

Rational Mind
- Approaches knowledge intellectually
- Thinks logically and uses past experience
- Uses facts and research as well as planning
- Focused

Wise Mind
- Intuitive thinking
- Arrangement and balance between Rational and Emotional Mind
- Living Mindfully

Emotional Mind
- Reason and logical thinking difficult
- Uses only emotions to make decisions
- Reactive
- Tells us how we are really doing
- Uses core psychological needs
Wise Mind Accepts Skills

The ACCEPTS Skill

- Activities: Contributing
- Comparisons: Doing something for someone else
- Emotions: Generating different emotions than the ones that you’re feeling
- Pushing away: Engaging in thoughts that compete with the ones present during the crisis
- Thoughts: Putting the problem on a shelf
- Sensations: Using the five senses in order to ground

IMPROVE the Moment

- I – imagery
- M – meaning
- P – prayer
- R – relaxation
- O – one thing mindful
- V - vacation
- E - Encouragement
Questions or Comments?

“Life doesn’t get easier or more forgiving, we get stronger and more resilient.”

Steve Maraboli

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Questions?

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References


