



## Coping with the Stress of Caregiving

Celebrating a Second Chance at Life  
Survivorship Symposium

April 17- 23, 2021



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University of Kansas Cancer Center

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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



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## 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)



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## 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



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## 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)

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## 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



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## 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)



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## 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.”



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## 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)



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## 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

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## 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

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## BMT Caregiver Distress Screening

**CAREGIVER  
NEEDS ASSESSMENT**

The University of Kansas Cancer Center is dedicated to taking care of each patient and their care team. As a caregiver, we want to assist you throughout your journey. Please complete the steps below.

Are you the primary caregiver to this patient? Yes  No

Relationship to patient \_\_\_\_\_ Date of Birth: \_\_\_\_\_ Preferred Phone: \_\_\_\_\_

Please affix label or complete below fields:

Patient Name: \_\_\_\_\_

MEN: \_\_\_\_\_

DOS: \_\_\_\_\_

Clinic Location (La, L.S., WW): \_\_\_\_\_

STEP 1	STEP 2	STEP 3											
<p>How distressed are you feeling today? Circle below to show your level of distress, 10 being the highest, 0 being the lowest</p> <p>10 _____</p> <p>9 _____</p> <p>8 _____</p> <p>7 _____</p> <p>6 _____</p> <p>5 _____</p> <p>4 _____</p> <p>3 _____</p> <p>2 _____</p> <p>1 _____</p> <p>0 _____</p> <p><small>4/18/21</small></p>	<p>Please mark YES if any of the following are concerns you have had in the PAST MONTH:</p> <table style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 10%; text-align: center;"><b>NO</b></td> <td style="width: 10%; text-align: center;"><b>YES</b></td> <td style="width: 80%;"> <p><b>Practical Concerns</b></p> <p>I need help finding a place to stay near the cancer center</p> <p>I need to be a caregiver for more than the patient</p> <p>I want to discuss work related issues (FMLA)</p> <p><b>Emotional Concerns</b></p> <p>I am feeling anxious, worried, or irritable</p> <p>I am crying more or feeling sad or depressed</p> <p>I am concerned about my relationship with people close to me</p> <p><b>Spiritual Concerns</b></p> <p>I have religious beliefs that impact my caregiving</p> <p>I have spiritual worries related to the illness of the person I care for</p> <p>I consider prayer/meditation/worship as important to my treatment</p> <p><b>Self-Care Concerns</b></p> <p>I have noticed significant physical changes in myself (i.e., weight, sleep)</p> <p>I DO NOT feel supported by hospital staff</p> <p>I DO NOT feel supported by friends/family</p> <p><b>Communication Concerns</b></p> <p>I DO NOT feel I understand the patient's condition and progress</p> <p>I DO NOT feel knowledgeable about the duties of me as a caregiver</p> <p>I have questions that need to be answered by the medical team</p> </td> </tr> </table> <p>We want to hear your feedback. 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Please mark all that apply to you.</p> <table style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 10%; text-align: center;"><b>NO</b></td> <td style="width: 10%; text-align: center;"><b>YES</b></td> <td style="width: 80%;"> <p>Support Group (disease, peers, etc.)</p> <p>Wellness Group (coping, yoga, etc.)</p> <p>Educational Opportunities</p> </td> </tr> </table> <p style="text-align: center;"><b>OFFICE USE ONLY</b></p> <p>The following referrals were made:</p> <table style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 50%; vertical-align: top;"> <p><input type="checkbox"/> Social Work</p> <p><input type="checkbox"/> Psychologist</p> <p><input type="checkbox"/> Dietitian</p> <p><input type="checkbox"/> Chaplain</p> <p><input type="checkbox"/> Exercise Specialist</p> <p><input type="checkbox"/> Financial Counselor</p> </td> <td style="width: 50%; vertical-align: top;"> <p><input type="checkbox"/> Turning Point</p> <p><input type="checkbox"/> Other</p> <p><input type="checkbox"/> Caregiver declined</p> <p><input type="checkbox"/> Need Not Indicated</p> </td> </tr> </table> <p>Care Team Signature: _____</p>	<b>NO</b>	<b>YES</b>	<p>Social Worker</p> <p>Psychologist</p> <p>Dietitian</p> <p>Chaplain</p> <p>Exercise Specialist</p> <p>Financial Counselor</p>	<b>NO</b>	<b>YES</b>	<p>Support Group (disease, peers, etc.)</p> <p>Wellness Group (coping, yoga, etc.)</p> <p>Educational Opportunities</p>	<p><input type="checkbox"/> Social Work</p> <p><input type="checkbox"/> Psychologist</p> <p><input type="checkbox"/> Dietitian</p> <p><input type="checkbox"/> Chaplain</p> <p><input type="checkbox"/> Exercise Specialist</p> <p><input type="checkbox"/> Financial Counselor</p>	<p><input type="checkbox"/> Turning Point</p> <p><input type="checkbox"/> Other</p> <p><input type="checkbox"/> Caregiver declined</p> <p><input type="checkbox"/> Need Not Indicated</p>
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## 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





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## 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

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[www.helpforcancercaregivers.org/content/caregiver-burnout](http://www.helpforcancercaregivers.org/content/caregiver-burnout)

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## Where do I start?



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## 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

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## 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”)

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## Caregiver Self-Care

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



Pain + non-acceptance= suffering



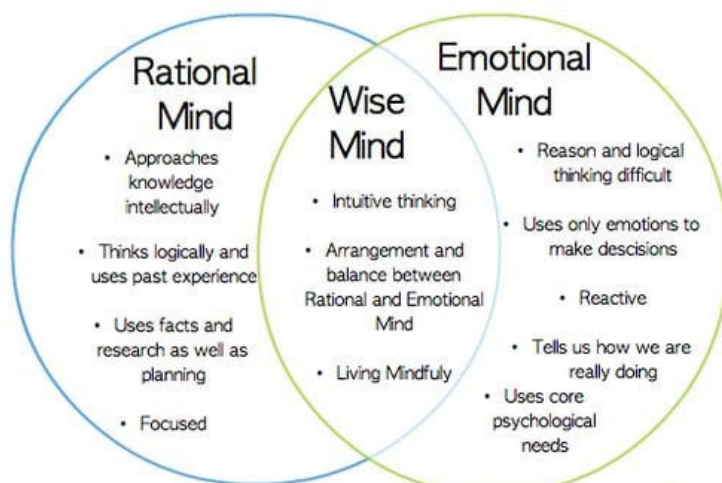
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## Skills



[online diagramming & design] [creately.com](https://www.creately.com)

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## Wise Mind Accepts Skills

### The ACCEPTS Skill

A	C	C	E	P	T	S
Activities	Contributing	Comparisons	Emotions	Pushing away	Thoughts	Sensations
	Doing something for someone else		Generating different emotions than the ones that you're feeling		Engaging in thoughts that compete with the ones present during the crisis	
Engaging in activities		Juxtaposing a previous worse period of your life with your current one		Putting the problem on a shelf		Using the five senses in order to ground

Linehan, M. M. (2015). DBT® skills training manual (2nd ed.). New York, NY, US: Guilford Press.

Psychotherapy Academy

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## IMPROVE the Moment

- **I** – imagery
- **M** – meaning
- **P** – prayer
- **R** – relaxation
- **O** – one thing mindful
- **V** - vacation
- **E** - Encouragement

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# Questions or Comments?



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# Questions?

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## References

- Jim, H.S., Quinn, G. P., Barata, A., Cases, M., Cessna, J., Gonzalez, B., Pidala, J. (2014). Caregivers' Quality of Life after Blood and Marrow Transplantation: A Qualitative Study. *Bone Marrow Transplantation*, 49(9), 1234–1236. <http://doi.org/10.1038/bmt.2014.118>
- Bishop, M.M., Beaumont, J.L., Hahn E.L. et al. Late effects of cancer and hematopoietic stem-cell transplantation on spouses or partners compared with survivors and survivor-matched controls. *Journal of Clinical Oncology* 2007; **25**: 1403–1411
- Kim, Y., Baker, F., Spillers, R. L., & Wellisch, D. K. (2006). Psychological adjustment of cancer caregivers with multiple roles. *Psycho-Oncology*, 15(9), 795-804.
- Simoneau, T.L., Mikulich-Gilbertson, S.K., Natvig, C., Kilbourn, K., Spradley, J., Grzywa-Cobb, R., Laudenslager, M. L. (2013). Elevated Peri-transplant Distress in Caregivers of Allogeneic Blood or Marrow Transplant Patients. *Psycho-Oncology*, 22(9), 2064–2070. <http://doi.org/10.1002/pon.3259>
- Siston, A.K., List, M.A., Daugherty, C.K., Banik, D.M., Menke, C., Cornetta, K., et al. (2001). Psychosocial adjustment of patients and caregivers prior to allogeneic bone marrow transplantation. *Bone Marrow Transplantation*, 27, 1181–1188
- Van Ryn, M., Sanders, S., Kahn, K., van Houtven, C., Griffin, J. M., Martin, M., ... & Rowland, J. (2011). Objective burden, resources, and other stressors among informal cancer caregivers: a hidden quality issue?. *Psycho-Oncology*, 20(1), 44-52.

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