CAREGIVER MARITAL STRAIN

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DISCLOSURES

Cooke – no disclosures
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Objectives

- Review care giving as an experience
  - Tasks
- Caregiver characteristics
- Common Issues of Caregiver Burden
  - Distress
  - Quality of Life
  - Caregiver Needs
- Spousal Dyadic Issues
- Resources
- Interventions
What is Care giving Like?

Experience

- Cancer is a significant stressor
- Transplant trajectory is uncertain
- Multiple episodes requiring constant adjustment.
- Transplant care is harder than any other cancer care giving
- High symptom severity
- More than 40 hours a week
- Long duration of care giving

Bevans & Sternberg, 2016
What is Care giving Like?

Tasks

• Medication management
• Assisting with ADLs
• Providing transportation
• Making meals
• Finances
• Role shifting of family responsibilities
• Advocate
• Symptom management
• Emotional Support

Bevans & Sternberg, 2016; Honea et al., 2008
Caregiver Characteristics

- Spouses are usually the main caregiver
- Care is 24/7
- Varied “family” caregivers with different levels of involvement
- Care giving can negatively affect caregiver’s physical and psychological health
  - Immune issues
  - Coronary heart disease
  - Early death
- High demand of care may continue 1-6 years after transplant
- Most are novices at care giving

Bevans & Sternberg, 2016;
Common Issues of Caregivers
Distress in transplant: Care giving

• More distress pre-transplant
  – 88% pre-transplant to 18% at one year

• Predictors of distress
  – Female caregivers
  – Greater subjective burden
  – Greater patient symptoms
  – Avoidance coping
  – Allogeneic versus autologous
  – Unpredictable course

Beattie and Lebel, 2011
Caregiver Quality of Life

Physical

- Fatigue/constant vigilance
- Cognitive function
- Sexual dissatisfaction
- Sleep issues
- Difficult balancing their own health issues with the patient

Cooke, Gemmill & Kravits, 2009; Gemmill, Cooke, Williams and Grant, 2011
Caregiver Quality of Life

Psychological

- Fear of recurrence
- Fear of the future
- Depression
- Anxiety
- Uncertainty
- Appraisal of situation affects ability to cope

Cooke, Gemmill & Kravits, 2009; Gemmill, Cooke, Williams and Grant, 2011
Caregiver Quality of Life

Social

• Tension in the family
• Isolation from social networks
• Financial Concerns
• Role redistribution
• Inability to meet work demands

Gemmill, Cooke, Williams and Grant, 2011
Caregiver Quality of Life

**Spiritual/Existential**

- Fear of death
- Search for meaning and purpose
- Spiritual crisis/distress
- Better experience is linked to
  - Ability to re-order priorities and gain new insights
- Positive spiritual coping
  - Acceptance, staying positive, looking at life differently, setting goals, and praying

Gemmill, Cooke, Williams and Grant, 2011
Spouses as Caregivers
The Experience of Spouses as Informal Caregivers for Recipients of Hematopoietic Stem Cell Transplants.
Wilson, Margaret; PhD, RN; Eilers, June; PhD, RN; Heermann, Judith; PhD, RN; Million, Rita; BSN, RN
DOI: 10.1097/NCC.0b013e31819962e0
The Experience of Spouses

Common Needs of Spouses

- **Information**
  - To manage the uncertainty
  - To give more control for symptom management
- **Support**
  - From friends
  - From professional
- **Communication**
  - Buffering between partners can have negative impact

Northouse and McCorkle, 2010
The Experience of Spouses

Common Needs of Spouses

- Effective Coping
  - Active coping is better
    - Problem-solving, positive reframing, planning, acceptance
- Self-Efficacy
  - Confidence in their own ability
- Relationship-Focused interventions
  - To enhance the spousal dyad coping

Northouse and McCorkle, 2010
Opening Pandora’s Box

• Exploratory mixed method longitudinal study
  – on effect of care giving on health,
  – level of burden/depression/trauma,
  – time of vulnerability.
• Sample of 11 spouses
• Caring for a critically ill spouse was something never envisioned
• Themes
  – Need for reassurance and hope
  – Uncertainty
  – Waiting: Black hole with no rules
  – Altered relationships: need for give and take

Sabo, McLeod & Couban, 2013
Five Year Longitudinal Study
Marital adjustment/satisfaction

- Prospective, longitudinal, quantitative
- 121 HCT couples
- Results
  - Overall largely satisfied
  - High pre-transplant emotional distress
  - Maladjustment increased in female spouses, and after transplant
  - Marital satisfaction indicated more decrease in female spouses
  - Marital dissolution
    - 7.3% divorce rate at 5 years with surviving couples

Langer, Yi, Storer & Syrjala, 2010
Additional evidence of the problem

- Older adults receiving assistance with physician visits and prescribed medications and their family caregivers: prevalence, characteristics and hours of care  
  - 2011 National Health and Aging Trends Study (NHATS)
  - N=7,197 participants living in traditional community residences
  - Weighted estimates represent approximately 33.4 million community dwelling Medicare beneficiaries ≥ 65 YO
  - Caregivers who assist with both physician visits and medication management
    - Provide 45.4 hours of help per week
    - 64.3% also assist with mobility or self care
    - > depressive symptoms
    - Perceive health status as “Fair / poor”
    - Older
    - Less education
  - 3 out of 5 care recipients of care have possible or probable dementia
Additional evidence of the problem

  - Two linked studies
    - 2011 National Health and Aging Trends Study (NHATS)
    - National Study of Care giving (NSOC)
      - 1,739 family and unpaid caregivers of 1,711 older adults with disabilities
    - Range 8.3 – 28.1 hours / week of care / assistance
    - Supportive services use low (about 1 in 4)
    - Caregivers providing substantial help with health care (physician visits and medication management):
      - Experienced more emotional, physical, and financial difficulty
      - Reduced participation in one or more valued activities due to care giving
      - Work productivity loss
Intervention

- A randomized control trial of a psychosocial intervention for caregivers of allogeneic hematopoietic stem cell transplant patients: effects on distress
- Addition of eight one-on-one stress management sessions during 100 days post HCT, compared to standard of care
  - Understanding stress, changing roles as caregivers, cognitive behavioral stress management, pacing respiration, identifying social support
  - Primary endpoints – perceived stress and salivary cortisol awakening response (CAR)
    - Lower caregiver stress at 3 months post HCT
    - Significant reduction in anxiety and depression
    - CAR did not differ between groups
Intervention


- **Patient / caregiver teams**

- **Three 1-hour problem solving education sessions**
  - Cancer Self-Efficacy Scale – transplant
  - Brief Symptom Inventory – 18
    - Caregiver responders
      - Improvements in self efficacy
      - Improvements in distress
      - Better health outcomes such as fatigue
Conclusion and recommendations

- Intensity, complexity, and duration of HCT care giving
  - Involvement across time and care settings
- Caregiver needs, preferences
- Caregiver resources, education

Wolff, Spillman, Freedman, & Casper (2016)
- Caregivers may be poorly informed about patients’ health or treatment plans
- Family members should be included as members of the patients’ interdisciplinary care teams
- More explicit and robust partnerships with patients’ family caregivers
- Although care is safer, more efficient, and of higher quality when delivered by a coordinated health care team, little attention has been directed at understanding the extent or consequences of coordination between health care professionals and family caregivers.
- Organizational strategies to more purposefully engage and support family caregivers.
Cancer Family Caregiver Websites...

5. CancerCare: http://www.cancercare.org/tagged/caregiving
7. Joe’s House: www.joeshouse.org
...Cancer Family Caregiver Websites

8. Leukemia & Lymphoma Society:  
   http://www.lls.org/support/caregiver-support?src1=21156&src2=

9. My Cancer Circle:  
   http://mycancercircle.lotsahelpinghands.com/caregiving/home/

    http://www.nccn.org/patients/resources/default.aspx & Patient and Caregiver Resources brochure:  
    http://www.nccn.org/patients/about/pdf/patient_brochure.pdf

11. National Cancer Institute (NCI):  
    http://cancer.gov/cancertopics/coping/familyfriends & Family Caregivers in Cancer PDQ®:  
    http://www.cancer.gov/cancertopics/pdq/supportivecare/caregivers/patient

12. The R. A. Bloch Cancer Foundation:  http://blochcancer.org/
### General Family Caregiver Websites...


2. **American Association of Retired Persons (AARP)**:  


5. **CarePages**: [https://www.carepages.com/](https://www.carepages.com/)

6. **Caring from a Distance**: [www.cfad.org](www.cfad.org)

7. **CaringBridge**: [www.caringbridge.org](www.caringbridge.org)

8. **CMS - Centers for Medicare and Medicaid Services (formerly HCFA)**:  

9. **Family Caregiver Alliance (FCA)**:  
   [http://www.caregiver.org/caregiver/jsp/home.jsp](http://www.caregiver.org/caregiver/jsp/home.jsp)

10. **Lots’a Helping Hands**:  
    [www.lotsahelpinghands.com](www.lotsahelpinghands.com)

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[the MIRACLE of SCIENCE with SOUL City of Hope]
11. National Alliance for Care giving (NAC): http://www.caregiving.org/resources
15. NICHE (Nurses Improving Care for Healthsystem Elders): http://www.nicheprogram.org/tiers?q=caregivers
17. UCSF Osher Center for Integrative Medicine: http://www.oser.ucsf.edu/patient-care/self-care-resources/caregivers/
19. Well Spouse Association http://www.wellspouse.org/support/caregiver-support.html (If link does not work, copy and paste)
If your loved one was just diagnosed with cancer, you might be wondering, “How can I help?” From driving your loved one to appointments to cooking meals to just being there to listen, caregivers face many challenges as they seek to provide important physical and emotional support to someone with cancer.

http://www.patientresource.com/Caregiving.aspx
The top 10 things you should know as a caregiver:

1. **Communicate openly**
   Healthy communication between you and your loved one living with cancer can reduce frustrations and help both of you manage difficult emotions, such as fear. Everyone communicates differently, so try using various techniques, including gestures, expressions and touch. Be realistic and flexible in your communication, always taking your cues from your loved one. And convey your openness to all conversations—even the tough ones.
2. Educate yourself
Many cancer patients might not understand – or are not ready to digest – the medical information associated with their diagnosis. As a caregiver, you may need to help interpret treatment options and manage physical symptoms, all with no previous medical training. It’s normal to feel unprepared to make informed decisions, but numerous resources exist that can help. Doctors, nurses and pharmacists are all helpful sources of information, so get to know the members of the health care team. Take notes and ask questions during visits until you gain a good understanding. Reputable cancer education websites can also help you self-educate.

3. Get organized
As a caregiver, you’ll likely be confronted with a lengthy list of practical life issues, such as providing transportation to appointments, talking with the medical team, managing the home, informing family members and delegating. Paying for expensive medications and monitoring insurance coverage also become important issues. To help you organize all of these new responsibilities, encourage family conferences to discuss roles and logistics and to get everyone on the same page. See Financial Help for Patients & Families for a list of financial resources.
4. Don’t “overfunction”  
Due to side effects and hectic appointment schedules, you’ll need to assume many of the jobs formerly done by the patient. Initially, you may have a tendency to overfunction for your loved one in an attempt to help as much as possible. However, try to not do anything as a caregiver that the patient is capable of doing alone. Evaluate your loved one’s ability and willingness to participate in daily self-care and go from there. Do your best to keep life as normal as possible, and let your loved one decide when help is needed.

5. Embrace change  
Cancer is not always predictable, so what you hope for as a caregiver may need to change throughout the course of your loved one’s battle. You may have a lofty hope for a return to normalcy one day and a simple hope for less suffering the next—and that’s okay. Just do your best to remain realistic and flexible. Also do your best to embrace the reality that traditions, especially around the holidays, can’t always be carried out. Instead, make new ones to cherish and look for ways to treasure each day just as it is.

6. Remember your own basic needs  
Many caregivers experience both physical and emotional fatigue, often neglecting their own needs for nutrition, adequate sleep, exercise and socialization. Do not underestimate the toll this can take on your health and well-being. Stick to your normal routine as much as possible, and don’t feel guilty when you take time to care for yourself. This will allow you to better care for your loved one.
7. Plan time for yourself
Set aside time each day to do something you enjoy. Meet a friend for lunch, take a walk or watch a funny movie. Most importantly, don’t think of these activities as selfish. It’s imperative to occasionally escape from your duty as caregiver. Research is showing that self-care is medically necessary to keep yourself physically and mentally strong.

8. Ask for help
It’s not realistic to think you can do it alone. Family and friends often want to help, but they may not know how. To focus their desire, create a clear list of areas where you could use a hand and ask them which tasks they’d like to tackle. Continue to reach out until everything is covered. Asking for help can relieve some pressure and leave you with a little time for yourself.
9. Seek out support
Many caregivers have to suspend their own lives and report feelings of loneliness and isolation. About one-third say they have some strain or stress on their social and physical well-being, including anxiety, depression, spiritual challenges and sleep problems. Although the caregiver’s depression can be at almost the same level as the patient’s, many caregivers don’t realize that they need support, too. Don’t overlook the local support groups or educational programs offered by many cancer centers. Many outstanding resources on the Web can also be beneficial. Talking with other caregivers – either in person or online – can help provide the support you need.

10. Enjoy your role
While care giving will likely be the hardest job you ever do, it may also bring you closer to your loved one living with cancer. Care giving allows you to demonstrate your love and respect, and it can give you a deep sense of satisfaction and accomplishment. Through care giving, you may find a new sense of purpose in life, and you’ll undoubtedly learn things about yourself that you didn’t know before.