

Practical Advice for Caregivers Recovery after Transplant

Liz Cooke RN MN ANP AOCN
Nurse Practitioner and Senior Research
Specialist

Department of Nursing Research
City of Hope Medical Center



Lecture outline

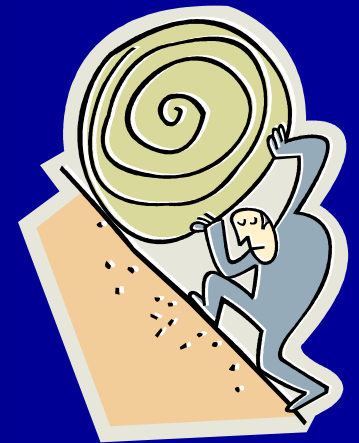
Path for the Journey



- Caregiver Characteristics: Who are caregivers?
- Transplant first year: How is the first year after transplant experienced?
- Long-term Issues: What are caregivers saying long-term?
- Interventions: What can caregivers do to "bounce-back"?

Caregiver Characteristics...

- Extension of the cancer workforce
- 24/7 job
- Family members provide 75% of the caregiving
- Both older and younger caregivers
- 31% find experience difficult
- 70-80% want more information



...Caregiver Characteristics

- Jobs include:
 - Medication organization
 - Symptoms management
 - Meal preparation
 - Coordination of services
 - Emotional Support
 - Medical Liaison to team
 - Supervision
 - Plus more...



Characteristics of the First Year After Transplant

- Unpredictable
- Non-linear recovery
- Roller coaster of events
- Recovery can be slow
- Long-term issues are not uncommon
- Emotional needs of the survivor can be overwhelming



Helder, et al, 2004; Hendricks, et al, 2002;
Hjermstad, et al, 2004; Kopp, et al, 2005;
Wingard, 2003; Worel, 20020

Life after Transplant: Negative impact on the caregiver...

- Slower recovery of psychological health than the patients
- Psychological health issues include anger, depression, anxiety, grief, worry, PTSD
- It is not unusual to have physical health issues such as pain and fatigue
- Employment and financial strain common
- Self-care suffers
- Social isolation

Cooke, et al., 2009



Life after Transplant: ...Negative impact on the caregiver

- Existential /Spiritual crisis issues
- Fear of loss and vulnerability
- Age affects the distress
 - Younger caregiver describe role juggling
 - Older caregivers describe balancing their health issues with that of the patient
- Tension can occur in families under stress



How can caregivers bounce back from the transplant experience?

Caregiver



Stressor of
Transplant



Coping
Outcome



Mediating factors that
Promote resilience

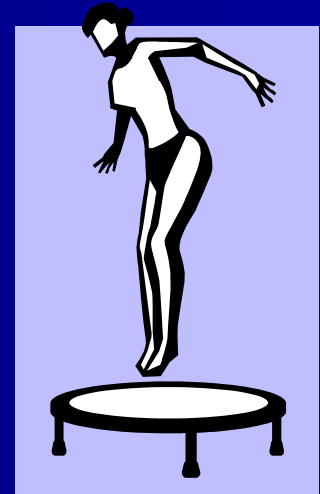
Some Effects of Stress

- Simple changes in cognitive issues such as memory
- Effects executive function: organization, logic, reasoning
- Can change the ability to regulate emotions and behavior
- Depletes energy
- Effects the neuroendocrine system of cortisol overproduction and hyperactivation



How can caregivers bounce back from the transplant experience?

- Physical
- Psychological
- Marital
- Social
- Spiritual/Existential



Physical Ways to Restore

- “Mom’s advice”:
 - sleeping at least 8 hours/day
 - Regular healthy meals
 - Periods of rest balanced with play
- Moderate exercise 4-5 times a day for at least 20 minutes
 - This is done to combat the extreme fatigue
- Regular medical and dental care
- Active management of physical symptoms
- Health promotion: immunizations



Psychological Ways to Restore

Tips that have shown better coping

- Focus and build on strengths rather than deficits
 - Example: "learner" so enroll in a fun class
 - Example: "competitor" so play on a team
 - Example: "intellectual" so learn a new language
- Build Hope
 - Plan regular moments to look forward to; "up-ticks" in your schedule
 - Dinners with friends
 - Short or long trips
 - Events to build joy



Psychological Ways to Restore

Tips that have shown better coping

- Cognitive methods of how the event is viewed (appraisal)
 - Gratitude
 - Benefit-Finding
 - Optimism
- Build Resilience
 - Find meaning in the experience
 - Write a legacy journey for children or yourself: what was learned, who helped, what the growth was, etc.



Psychological Ways to Restore

Tips that have shown better coping

- Evaluate ways to cope that may be helpful
 - Anger management classes
 - Counseling
 - Cognitive-Behavioral Therapy
 - Communication classes
 - Group Support therapy
 - Individual therapy
- Locus of Control (way to measure personal control)
 - Internal versus external



Psychological Ways to Restore

What is better coping ?

- "Fighting Spirit"
 - meeting the challenge
- Acceptance:
 - being in the moment and moving forward
- Active vs. passive
 - not hiding and facing the challenge of stress
- Humor
 - Trying to lighten the atmosphere and mood



Psychological Ways to Restore

What is better coping ?

- Planning
 - Moving forward, future direction
- Cognitive Reframing
 - Evaluating the thought process
- Self-Distraction vs. denial
 - Moving the mind off rumination
- Use of Religion
 - comfort
- Venting
 - Debriefing reduces stress



Psychological Ways to Restore

Less helpful coping responses

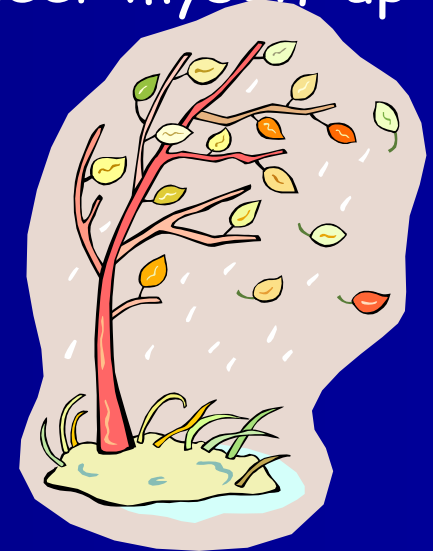
- Denial
 - Refusal to accept truth that can't be changed
- Anxious Preoccupation
 - Constant worry
- Fatalism
 - Sees no positive
- Helplessness/Hopelessness
 - No role in change, lack of control
- Avoidance
 - Will not face stressor



Psychological Ways to Restore

Less helpful coping responses

- Substance Use
 - Alcohol, cigarettes, illicit drugs
- Behavioral disengagement
 - "I feel I can't do anything to cheer myself up"
 - I feel that life is hopeless"



Marital Ways to Restore

- Partner's distress level mirrors patients, can come later, and is affected by dissimilarity with patient's response
- Is there "protective buffering"
 - hiding cancer-related thoughts and concerns from spouse/partner
- Motivations for buffering:
 - Decrease the strain on the patient
- Consequences of buffering
 - Decreases marital satisfaction
 - Decreases mental health



Marital Ways to Restore

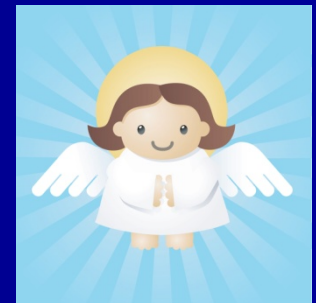
Redefine Balance in marital relationship

1. Sexual and intimacy needs
2. Active engagement , problem-focused, good communication
3. Re-establishing independence
4. Re-define the roles of the household
5. Female caregivers more at risk
6. Realize the interconnection between partners



Spiritual Ways to Restore Definition

"Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness too the moment, to self, to others, to nature, and to the significant or sacred."



Spiritual Ways to Restore

- Assess whether your spirituality has changed since the diagnosis of cancer?
- Reach out to chaplain, clergy, rabbi, minister
- Are spiritual practices important to you?
- Has the road been meaningful for you or difficult?
- Power of "bearing witness" and "compassion in action"



Social Ways to Restore Social Support

- Development of positive nourishing relationships serve as a buffer to stress
- Regular support groups provide a place to debrief and provide a sense of common experience
- Many environments: church, temple, sororities, clubs, organizations, classes, hobbies of interest



Social Ways to Restore Social Support



- Consider the role of culture, and the expectations of culture
- Feelings of isolation may occur even with social support, face to face peer support may be helpful
- Identify role models who are resilient
- Relinquishing control
- Consider giving back
- Pursue leisure activities