Cancer’s Impact on the Family & Caregivers

Moving Beyond Cancer to Wellness
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Objectives

By end of presentation, you will be able to:

1. Describe the impact of cancer on spouse-caregivers’ and children’s adjustment
2. Identify what is known from research that positively affects families’ adjustment
3. Describe practical ways families can enhance their quality of survivorship
4. Identify community resources to add to families’ quality of survivorship
Cancer causes ripple effects in the family.
Cancer is a personal experience for the family, not a medical event.

Wimberly et al, 2005

Stressors & threat activate interpretive processes in CNS.

CNS triggers fight-or-flight in autonomic nervous system (ANS) or defeat-withdrawal thru HPA.

Antoni et al, 2006
Why is patient & caregiver distress important?

Over long periods, neuro-endrocrine activity in patients can alter tumorigenesis & production of growth factors & other cell growth regulators.  

Antoni et al, 2006, p. 243

Spouse caregivers are at risk for biologic dysregulation of their inflammatory pathways.


Spouse caregivers’ cancer-related pressures negatively impact marital communication over time.  

Fletcher et al, 2010
What is the evidence?

What is known about the impact of cancer on the family? on the spouse-caregiver?
“I feel as though I’m not necessarily… I’m not doing the job that I’m here to do, to help her and protect her…”

Spouse of patient
Distress in Spouse Caregiver

“The emotions are the things that I seem to be unprepared for…and I want to be sensitive to those emotions and I don’t want to react negatively…Like when she gets hostile in words…In fact, she’s saying, ‘I am feeling bad, listen to me.’ Instead, I misinterpret that and fire something back at her…”
“I think it has affected me not only emotionally, when we first heard….but it had a physical effect on me, too. I think I’ve lost some hair over it...I just felt tired and no energy. Maybe that was depression.”
**What Predicts Spouse-Caregivers’ Depressed Mood**

<table>
<thead>
<tr>
<th>Significant predictors:</th>
<th>Std. Beta</th>
<th>t-statistic</th>
<th>p-value</th>
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<tbody>
<tr>
<td>Spouse marital adjustment</td>
<td>-0.28</td>
<td>-4.78</td>
<td>&lt;.001</td>
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<tr>
<td>Job-related concerns</td>
<td>0.28</td>
<td>4.63</td>
<td>&lt;.001</td>
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<tr>
<td>Concern for wife’s well being</td>
<td>0.15</td>
<td>2.44</td>
<td>.02</td>
</tr>
<tr>
<td>Feeling excluded from med team</td>
<td>0.11</td>
<td>2.14</td>
<td>.03</td>
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<tr>
<td>Illness-related uncertainty</td>
<td>-0.26</td>
<td>-4.15</td>
<td>&lt;.001</td>
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Overall Model F-Statistic 16.32, p<.001  
Adjusted R-square 0.50  

*Lewis & Fletcher, 2008, JCO*
Severe depression in male caregivers of women with breast cancer.

Retrospective cohort study. Unbiased, nationwide, population–based data.

Male partners of women with breast cancer had increased risk of being hospitalized with affective disorder (hazard ratio 1.39) with a dose response pattern for severity of breast cancer.

Feeling nailed by the cancer:
feeling helpless to save their wife;
lacking sleep because of supporting
her; being overwhelmed with her
emotions and how to support her

Zahlis & Lewis, 2010
Couple-time is given low priority.

“Our relationship has changed the cancer….It’s like everything takes priority over us spending time together, just the two of us.”
“We fight more, argue more. Any little thing whatever, upsets her, which is just about anything.”
47% of couples have poor marital adjustment with local recurrent breast cancer

Lewis & Deal, 1995

66% of couples want to work on ways to better deal with tension in their marriage or be together as a couple with breast cancer

Shands et al., 2006
Dealing with tension in the relationship from the breast cancer
Dealing with the illness’ unpredictable nature
Dealing with feelings of loss
Managing the possibility of recurrence
Sharing the illness with others
Anticipating the anniversary date of the diagnosis
Establishing sexual intimacy
Common “Stuck Points” between Patients & Spouse Caregivers

- Dealing with well-meaning friends or family that hurt
- Sharing the cancer with others
- Sharing feelings with each other about the cancer
- Handling expressed anger at the other
- Dealing with divergent models of healing from the cancer
- Getting & using social support outside family
What are tested strategies that improve the family’s adjustment?
Tested Programs for Couples Impacted by Breast Cancer

United We Stand

Helping Her Heal

Helping Us Heal

United We Stand

3-group RCT:
- Medical education control
- Individual coping training for patient
- Couples-based conjoint coping training – CanCope

CanCope: Significant improvements in couples’ supportive communication [observed], coping effort [self-report], and improved sexual adjustment [self-report]

Scott et al., 2004
<table>
<thead>
<tr>
<th>Observational code</th>
<th>Definition</th>
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<tr>
<td>Criticism</td>
<td>Expressions of dislike or disapproval or statements likely to demean the listener</td>
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<td>Disagreement</td>
<td>Direct disagreement or “Yes, but” type disagreements</td>
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<tr>
<td>Withdrawal</td>
<td>Not tracking, not responding, turning away, statement of not wanting to discuss the issue</td>
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<tr>
<td>Warmth</td>
<td>Voice tone, facial expression, or body posture that convey warmth and caring (e.g., warm tone)</td>
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<tr>
<td>Validation</td>
<td>Demonstrations of acceptance of the other person by paraphrase, open-ended questions, positive feedback, or agreement with them by assent or direct agreement</td>
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<td>Couple coping</td>
<td>Statements about coping, partner support, or the cancer experience in the context of the couple relationship (e.g., “We make a good team,” “Our cancer scare has brought us closer,” “We can get through this if we take it a step at a time,” “We faced a steep learning curve trying to understand all the medical facts in a short time, but we did it”)</td>
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Tested Programs for Couples Impacted by Breast Cancer

Helping Her Heal

Helping Us Heal

Cochrane et al, 2011; Lewis et al, 2008; Lewis & Griffith, 2012
Helping Her Heal Program-HHH

Current Phase III clinical trial
5-sessions with spouse caregiver
on self-care and skill-building to support the patient

Cochrane et al., 2011; Lewis et al., 2012

Hush

Same program as HHH delivered by telephone.
What can help the family thrive?

*Kitchen table talk:* Put the cancer on top, not under, the table.

Ask
Listen
Honor
Tell
Ask: At the “kitchen table talk” ask each person to say how things are going for them about the cancer.
Listen: a special kind of listening that heals

Listen quietly & attentively.
Maintain eye contact.
Do not multi-task.

Do not “roll any tape” in your head.

Listening is special medicine! Sometimes that is all that is needed.
Thank each other for letting others know what they are going through.

_Do not skip this step._
Telling depends on what is shared…

Frame the cancer as specific and workable. Coach each other; share ways to manage specific concerns. Create a family metaphor that puts the cancer in a suitcase, not on the family’s “back.” Talk about strengths, not weaknesses.
Balance family life with the cancer

Cancer can take over….and before you know it, you have given up your life as a couple or as a family.
Balance family life with the cancer; your family is more than the cancer!
Put the cancer on top of the table.

Have regular “kitchen table talks” to check in with how each family member is doing with the cancer.
Take care of the caregiver

Recognize caregiver’s care....Use magic words like, Thank you....So appreciate....

When you recognize the caregiver’s care, it positively affects the caregiver’s ability to cope.

Stajduhar et al., 2008
Guide

Rx: Regularly take a “vacation” from the cancer; you are more than the cancer!

Rx: Build in intentional fun.

Rx: Give yourself 15 minutes a day minimum for decompressing and self-care.

Self-care is not selfish!
Rx: Check in with each other: How are you doing with this…?

Listen quietly & attentively.
Do not judge what is being said.
Do not try to problem-solve or “fix things.”
Respond to thoughts and feelings; do not try to redirect them.
Directly ask each other: What can I do to better support you?

Core Results for Parental Cancer & Dependent Children

- Depressed Mood
- Demands of Illness
- Family Coping
- Parent-Child Relation
- Child Function
- Family Function
- Marital Adjust
- Social Support
- SES
- Length Diagnosis
- Child Gender

- M/YC
- P/YC
- M/OC
- P/OC

J Behav Med ‘93
Fam Rel ‘96
Ill parents say they do not know how to respond or help their child about the cancer.
Not knowing how to help the children

“I was aware of the fact that the kids’ emotional needs had to take second place to mine and that was hard. With the fatigue, I just didn’t have enough energy to listen.”
“Well, at times I was really scared. And I remember sometimes crying and like...sometimes, she was really sick...And I didn’t want my mom to pass away.”

f-8yr/11yr
The majority (81%) of interviewed children were worried their mother would die from the breast cancer.

Zahlis, 2001
Help the children put the illness in their suitcase, not on their backs.

Photo courtesy of Phil Gelinas ©
Check in with your child about their questions or concerns.

Use open-ended questions to talk with your child about the cancer, not Yes/No questions.

Cancer is a dynamic illness, not a static disease. Protect “kitchen table” talks together on a regular basis.
Balance Family Life with Cancer

Identify and protect things that bring your family quality of life: What brings smiles to your faces or heart

Take a “vacation” from the cancer

Use support offered by others

Create new rituals & traditions

“Dance a lot…!”
Guide

Link with resources:
Cancer Lifeline: 1-800-255-5505

Gilda’s Club

Local support group
The ultimate goal is to thrive.