Supporting children through a parent’s life-threatening illness

North Shore Medical Center Family Rounds
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  Children’s	
  Coping	
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Today’s focus
• Talking to children about parental illness
• Supporting children’s resilient adjustment
• Seeking outside support

Supporting children through a parent’s life-threatening illness

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Illness changes how families function

• Re-organization of roles
• Disruptions to routines
• Parents less available, emotionally and physically
• Decline in income

Children with a medically ill parent

Parental cancer affects children, with some experiencing:
• internalizing or externalizing problems
  – depressed mood
  – irritability
  – preoccupying, intrusive thoughts
  – sleep problems
  – somatic complaints
  – peer conflict or withdrawal
  – Behavioral regression
• latency boys and adolescent girls may be at higher risk

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Not every child responds the same way to parental illness...
what factors promote resilience?

Resilience during parental illness

• Family characteristics
  – Marital satisfaction, reasonable expectations of child, flexible problem solving, clear roles, cohesion, stable finances, limited stressors
• Parent characteristics
  – Psychological adjustment (depression), open communication, warmth
• Child characteristics
  – Psychological resources, understanding of illness, social support, self-esteem, prior academic success

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(Osborn, 2007)

(Aslam, 2009; Gansler, 1996; Faulkner, 2002; Graham, 2007; Osborn, 2007; Sigil, 2009; Vescelius, 2010; Visser, 2005)

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MGH PACT program

(Cindy Moore, Ph.D.
Associate Director,
Marjorie E. Korff Parenting At a Challenging Time program)
Supporting Children’s Coping through a Parent’s Life-Threatening Illness

Supports to children’s coping

• Protected family time
• Normal routines
• Web of social support
• Open and honest communication

Protected family time

• Create some "illness-free" space for the family
  – Limit visitors, conversations about illness with others during family time
  – Limit phone calls during meals
• Focus on fulfilling roles you alone can do
  – Bedtime story reader, artwork admirer vs. chef, shopper
• Appoint 1-2 people to organize helpers and provide updates
  – Lotsa Helping Hands, Caring Bridge
• Look for new ways to have fun together

Normal routines

• Mealtimes, bedtime, school and after school
  – Fewer activities with good attendance preferable to more activities with spotty attendance
• Express interest in child’s activities
  – Sounds easy, surprisingly hard
• Utilize familiar caretakers
• School as haven/island of normalcy

Open, honest communication

Home

Find a private place to talk, at a time when children will not immediately need to regroup, and bring the family together

HONEST communication

Open-ended questions

Start by asking about children’s observations of changes in home life or the parent’s functioning, or what they understand so far about the illness

HONEST communication

Name the illness

• Describe treatment plans in age-appropriate language
• Avoid euphemisms
  – “Mommy has breast cancer and will be working with doctors to make the cancer go away.” (yes)
  – “Mommy has a boo-boo on her breast.” (no)
• Don’t flood children with details -- follow their lead

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### Supporting Children’s Coping through a Parent’s Life-Threatening Illness

**HONEST communication**

<table>
<thead>
<tr>
<th>Elicit emotions</th>
<th>Empathize with and validate a range of feelings</th>
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<tr>
<td>Specify impact</td>
<td>Describe concretely how the illness and treatment will impact the child’s life; plan how to minimize disruptions</td>
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**Answering questions**

- Welcome all questions warmly
- Is there a question behind the question?
  - Encourage elaboration
  - Questions and concerns
    - Often egocentric
  - Questions do not need to be answered immediately

**Impact of parental illness**

**Infants and toddlers (0-2 years)**

- Sensitive to changes in routine
  - May be more fussy, inflexible and easily frustrated
  - Heightened separation anxiety
- Aware of parent’s absence, but not the reasons for it
- Sensitive to emotional climate in the home

**Supporting infants and toddlers**

- Consistent caregivers and routine
  - Written instructions
  - Portable micro-environment
- Frequent brief visits with hospitalized parent
- Limit emotional conversations in child’s presence

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### Supporting Children's Coping through a Parent’s Life-Threatening Illness

**Impact of parental illness**  
**Preschoolers (3-5 years)**  
- Distressed by changes in routines, caregivers  
- Concerns are concrete and egocentric  
- May blame selves (or sibs) for illness  
- Regression is common  
  - Separation anxiety, toileting, bedtime  
- Disconnect between upsetting events and expression of strong feelings

**Supporting preschoolers**  
- Correct misperceptions and self-blame  
  - “How do you think Mommy got cancer?”  
  - “Sometimes kids worry that they thought or did something to cause the cancer. Kids never cause a mom’s cancer.”  
- Maintain preschool as island of normalcy  
  - Ask teachers to keep greetings upbeat  
  - Limit updates in child's presence  
- Monitor, but be patient with regression

**Impact of parental illness**  
**6-12 year olds**  
- Concerns are both egocentric and empathic  
- May worry about contagion, impact of stress, unfairness of illness  
- Better able to compartmentalize and distract, escape in school and activities  
- May express strong emotion, then act embarrassed & avoidant  
- Feelings also expressed indirectly (messy, stubborn, argumentative)  
- Questions may be blunt, detailed  
- Embarrassed to seem different  
- Somatic complaints frequent  
- Thinking often concrete  
  - “Walk for a cure”

**Supporting grade-schoolers**  
- Provide simple explanations of dx and tx  
- Dispel misconceptions re: contagion & causes of illness  
  - “You can’t catch cancer, like you can’t catch a broken leg”  
  - “Dad’s being mad at you for your report card didn’t cause his cancer”  
- Differentiate effects of illness vs. treatment  
- Support consistent engagement in school, activities and friendships  
- Don’t link all child’s complaints with parent’s illness

**Impact of parental illness**  
**Adolescents (13-18 years)**  
- Mature thinking => adult-like worries  
- Variable capacity to be helpful/ empathic/ “mature”  
- Parentification  
  - adolescent girls with ill mothers have highest levels of distress (Compas, Worsham, Ey & Howell, 1996)  
- May feel anxious, sad, angry  
  - poor concentration, withdrawal  
- Reliance on friends and outside adults  
- Normative conflict with parents may increase guilt, or the feeling that the “wrong” parent is ill

**Supporting adolescents**  
- Don’t impose adult responsibilities  
- Respect teen’s coping style, wish for privacy  
- Watch for signs of depression, substance abuse, increased risk-taking  
- Foster relationships with trustworthy adults  
- Parents' honesty allows informed decisions, based on emerging values

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Supporting children at school

- Tell teachers what child knows, and wants others to know
- Discuss how information will be shared with staff, other parents
- Request that teachers be attuned to school materials or events related to illness
  - Science curricula on cancer
  - Literature with illness/death themes
  - Health class presentations
  - Parents' Night, Mother's Day
- Ask teachers to listen, not probe, and share child’s comments
- Facilitate child’s having the “Right Stuff”
  - Utilize other parents

When/Where to Refer

- Change in mood, behavior, or functioning for >2 weeks
- Worsening or recurring difficulties from a pre-existing condition
- The child requests additional support
- Risky behaviors or other safety concerns, such as suicidal thoughts. If so, an immediate evaluation is necessary.
- Sources: pediatrician, insurance plan, school, community supports, ED, etc.

Resources

Books:
http://www.cancer.org/cancer/bookstore/acp-books-for-children

Websites:
MGH Marjorie E. Korff PACT program: www.mghpact.org

References
