When Your Patient is a Parent: Guiding Parents to Support their Child’s Well-Being

Paula K. Rauch MD
Timothy Christopher Davidson Chair of Psychiatry
Marjorie E. Korff PACT Program
(Parenting At a Challenging Time)

www.mghpact.org
Parental Cancer is NOT Rare

- More than 18% of cancer patients in the US have dependent children
- Approximately 3 million children in the US live with a cancer survivor
- 55 thousand children in the US experience the death of a parent each year
  - (Weaver et al, 2010)
Significant Stressor

• Multiple studies show that patients with cancer and minor children experience greater stress

• Survivors with children worry more about recurrence
  – Ares et al, 2014

• Inadequate data on fathers
  – Oneill 2013

www.mghpact.org
Effects on the Parent

- **PCQ**

- **Parental depression and anxiety symptoms increase**

- **Quality of life for parents decreases**
  - Moore et al, 2015, Muriel et al, 2014

- **Satisfaction in their parenting role decreases**
  - Cho et al, 2014

*Even early stage cancer is associated with worry about how child would cope with parent’s death*  
*Asbury et al, 2014, Muriel et al, 2012*
Effects on the Child

• A range of concerns including distress about missed activities and peer interactions

• Changes seen in the parent

• Potential for death or separation

• Their own risk for cancer
Impact on Children

• Mental health care increases especially if either parent has psychiatric illness
  – Niemela et al, 2012

• Greater symptoms of anxiety or depression, intrusive thoughts, somatic complaints, and difficulty concentrating at school

• Evidence is mixed about externalizing behaviors
Child Adjustment is affected by

- **Illness related parental disability**
  

- **Healthy parent related quality of life**
  
  Krattenmacher et al, 2014

- **Parental depression or anxiety (impacts child and family functioning)**
  

- **Interventions help**
  

*Stage of Ca/ type of Ca not an independent factor*
Communication Literature

- Open communication is a positive influence

- Negative assessment of family + poor communication has worst impact on teens

- Positive assessment mitigates communication limitation
  - Schuler et al, 2014

- Parental perspective on communication is multi determined
  - Asbury et al, 2014
Protect or Exclude?

• Fear difficult questions especially about death
  (Barnes et al, 2000)

• Practical easier than emotional to discuss
  (Shands et al, 2000)

• Children and teens want to know about parent’s illness
  (Thastum et al, 2008)

• Bereaved children: wish to have been told about a parent’s approaching death
  (Bylund-Grenklo et al, 2014)

Adults who lost a parent in childhood: unpublished

www.mghpact.org
Parent guidance: Unmet Need

• Parents with cancer: 9% received family centered help
• Same group: 73% expressed the need for help
  • Ernst et al 2013
• International guidelines in Australia and England identify the need for parenting concerns to be addressed
• Recommendation of the Institute of Medicine in US for Breast Cancer Care
Resilience: Triad of Protective Factors

• Positive temperament (sociable, flexible, related)

• Family warmth and primary caregiver attunement

• Social support surrounding the child and family
  – Microanalysis of stress affected vs stress resilient children (Kilmer et al, 2001)

Resilience is the responsibility of the caring adults in the life of a child

www.mghpact.org
PACT Program: Parent Guidance

- Caregiver attunement supports resilience
- Parents know their children well
- Parents have a long relationship
- Parents can be advocates to engage the social support of the communities

- Parent guidance is effective when the parent has the emotional reserve to focus on the child and the child is relatively emotionally healthy
Marjorie E. Korff PACT Program

• Free Parent Guidance: Individualized psycho-educational intervention (Typically 2-4 sessions)

• 2 FTE of child trained mental health clinicians

• Approximately 300 new families seen yearly plus continued care of families

• Supported by philanthropy and the MGH Cancer Center
  – Program endowment + chair endowment

• Intervention assessment currently underway

www.mghpact.org
PACT Model: Resilience

• Child experiences a parent’s illness through the lens of her stage of development, temperament and her individual challenge

• Family capacities including cohesion and parental attunement support child resilience

• Community supports the child and family including school, church, afterschool and neighborhood
The PACT Model: Resilience Support Matrix

Parents

Developmental Stage

Siblings

Challenge

Temperament

Community

School

Faith

Afterschool

www.mghpact.org
Ten Years

- More than 2500 families
  - 55% mothers with cancer: 45% fathers
  - Average age 47 (range 22-74)
- More than 5000 children
  - By the numbers
  - Clinical impression

500 patients referred by > 150 individuals
Illness Related Factors

• Diagnosis
  – 22% GI, 20% Breast, 13% Lung
  • Parenting with breast cancer disproportionately studied

• Stage of Illness
  – 27% new dx, 40% active tx, 6% recurrence, 25% end of life
  – >50% metastatic disease

• Chief Concern and Site of Initial Consultation
  – 63% communication, 12% child coping, 10% end of life, 2% child behavior
  – Inpatient 35%, Outpatient 31%, Phone 26%, Infusion 9%
Healthcare Providers

• Parents want help from health professionals in how to talk with their children

• Nurses express a desire for more information about how a parent’s cancer affects children

• Adult healthcare providers rarely have child development education and guidance in how to help parents navigate parenting challenges
Lessons Learned from PACT
Five Questions to Ask a Parent

• What have you told your child? (Actual words used)
• Tell me about how your child has faced other transitions?
• Do you have any specific worries?
• Are there helpful or unhelpful lessons learned so far?
• Are there conversations you are afraid of having?
Three Key Arenas Support Childhood Coping

• Supporting the child’s normal routine
  – Emphasis on predictability during uncertainty
  – Keep as much the same as possible
• Protecting family time and routine
  – Save energy for the children
  – Be cautious about focus on outsiders
• Facilitating communication
  – Learning new skills (scripts)
  – Prioritize best talking times
General Recommendations

• Captain of kindnesses

• Ministers of information
Open Communication

• Name the cancer and explain cancer
  – Lego, weeds
  – Breeds of dogs
• Tease out the questions behind the questions
  – Many conversations not just one
• Prioritize the best times to talk
• Questions do not need to be answered immediately
Communication

• Provide psycho education about emotions
  – Waves
  – Parent waves and child waves
  – Living with uncertainty
• Iterate the parent child communication plans
  – Loving guess first
  – Following child’s wishes with experience
• Share changes when the occur and offer some assurance if nothing is imminent.
  – Try to establish security when time is precious
Childhood is a long hike uphill
Developmental Stages

- Infancy (0-2.5)
- Preschool Years (3-6)
- Elementary School Years (7-12)
- Adolescence (13-19)
- Young Adults
Infancy

• Attachment and Non verbal security
• The narrative of experience occurs later
• Create the documents for later use
  – Photos/ annotated albums
  – Videos
  – Letters
  – Journals
Parenting Tips

• Maximize consistency in caretakers and routines
• Educate parents about an infant’s capacity to manage separation from one parent
• Create a portable familiar environment
  – Portable crib with sheet, blanket and music
  – Diaper bag with treats and formula
Preschool Years

- Children weave together fantasy and reality (associative logic)
- Children are egocentric
- Associative logic + egocentricity = Magical Thinking = I am to blame

*Preschoolers are likely to feel responsible for parental illness*
Parenting Tips

- Maintain routines and loving limit setting
- Institute bedtime rituals
- Expect disconnect between content and feelings
- Encourage imaginative play
- Don’t interpret behavior
  - “You really don’t like peas for dinner.” (yes)
  - “It’s my melanoma, not peas, upsetting you.” (no)
Latency (Ages 7 to 12)

- Mastery of skills (sense of agency)
- Rules and fairness
- Best friends
- Talkers and internal processors
- Simple cause and effect logic
  - Illnesses must be contagious
  - Cancer must be caused by cigarettes
Parenting Tips

• Give simple what and why explanations
• Explain which are treatment symptoms
• Tell the school about the challenge at home
• Utilize a class parent or friend’s parent
• Ask teachers to listen, but not to probe
• Ask teachers and friends’ parents to share the child’s comments
Parenting Tips

• Protect family time by limiting visitors and turning off phones at meal times
• Encourage conversations with adult friends when the children are at school or after bedtime
• Set up weekly review times for the child to show the ill parent the accomplishments of the week: Attend to the details
Adolescence

- Mature (Abstract) Thinking
- Theoretical understanding and behavior are not on the same plane
- Normally teenagers confide in non parental adults
- Often have a more conflicted relationship with one parent than with the other
Parenting Tips

• Be cautious about assigning teens a parenting role with younger siblings
• Be cautious about making daughters caretakers
• Support relationships with caring adults outside of the family
• Utilize written schedules for chores and messages
Parenting Tips

• Be attuned to signs of depression, substance abuse, or risk taking
• Respect a teen’s coping strategy
• Articulate the complexity of finding personal balance
  – “Are you hearing too much or too little?”
  – “Are you home too much or away too much?”
Young Adults

• Parenting does not stop at 18
• Young adults need more information and a longer time line to make age appropriate decisions
• Romantic relationships may be more intense and break ups more challenging
• Be cautious about creating later guilt or regret with ambiguous expectations

It is not disloyal or uncaring to thrive or have fun
Parental Cancer: Challenges Not Traumas

• Challenges: Adversity with connection
  – Faced with the support of connected caring others
  – Builds life skills and results in greater self confidence

• Trauma: Adversity alone
  – Faced feeling alone, isolated and helpless
  – Results in fear and insecurity

*Parental illness can become a trauma for the children or can become a challenge*
Free PACT Resources

- [www.mghpact.org](www.mghpact.org)
  - Dozen Lessons Learned (can be used as brochure)
  - Parenting Principles
  - School Professional Toolkit
- [www.stayingstrong.org](www.stayingstrong.org) (military focus/multiple videos)
Additional Resources

• Teenagers

• Young Children
  – Arthur (English and Spanish) LiveStrong

• Parents
  – Cancer.net Patient education resources