



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

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(Parenting At a Challenging Time)

Disclosures

- I receive royalties from McGraw-Hill Publishing for authorship of *Raising an Emotionally Healthy Child When a Parent is Sick*.
- I am a paid consultant for Public Broadcasting Station WGBH on the cartoons “Arthur”, “Curious George”, “Molly from Denali”, “Pinkalicious”
- No other disclosures

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
 - Moore et al, 2015, Park et al, 2015, Bultmann et al, 2014, Bell and Ristovski- Slijepcevic, 2011, Nilsson et al, 2009
- Survivors with children worry more about recurrence
 - Ares et al, 2014
- Inadequate data on fathers
 - Oneill 2013

Effects on the Parent

- PCQ
 - Moore et al 2015, Muriel et al, 2014, Inhestern et al, 2016, Park et al 2017
- Parental depression and anxiety symptoms increase
 - Moore et al, 2015, Park et al 2015, Muriel et al, 2014
- 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
 - Visser et al, 2014, Bradbury et al, 2012)

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

Visser et al, 2005, Watson et al, 2006, Nelson and White, 2002, Rainville et al, 2012

- Evidence is mixed about externalizing behaviors

– Visser et al, 2005, Watson et al, 2006, Hoke, 2001, Jantzer et al, 2013

Child Adjustment is affected by

- **Illness related parental disability**

Bultmann et al, 2014, Krattenmacher et al, 2012, Osborn, 2007

- **Healthy parent related quality of life**

- Krattenmacher et al, 2014

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

- Bultmann et al, 2014, Gotze et al, 2014, Krattenmacher et al, 2012, Lewis and Darby, 2003, Schmitt et al, 2008

- **Interventions help**

- Lewis et al, 2015, Cessna et al, 2016, Phillips and Prezoie, 2016

Stage of Ca/ type of Ca not an independent factor

Communication Literature

- Open communication is a positive influence
 - Lindquist et al, 2007, Watson et al, 2006
- 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

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

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*

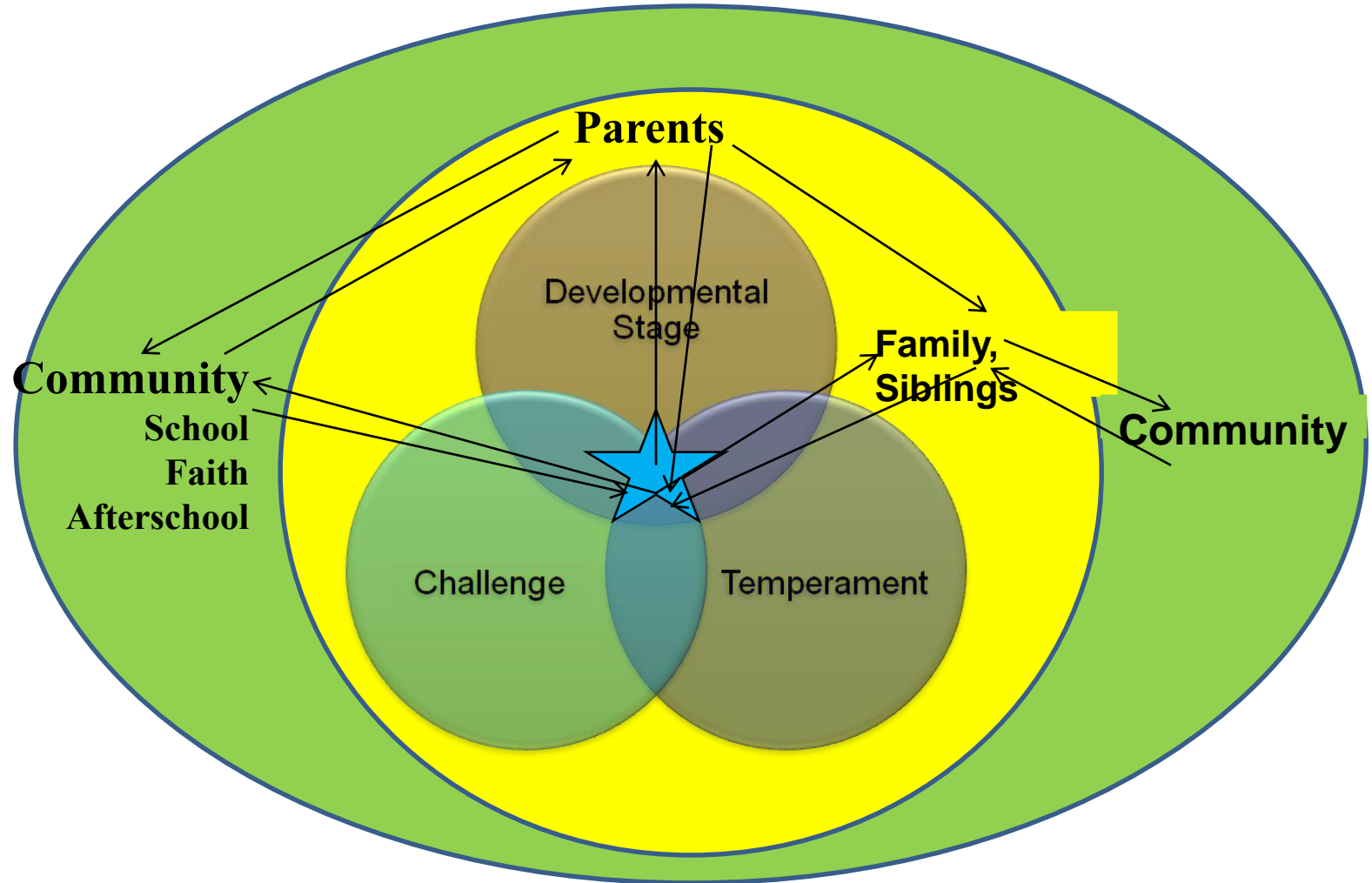
Marjorie E. Korff PACT Program

- 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
- Training to clinicians has been provided through online teaching, workshops and program supervision

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



Ten Year Snapshot

- 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 they 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
 - Dozen Lessons Learned (can be used as brochure)
 - Parenting Principles
 - School Professional Toolkit
 - Moore and Rauch. *Community Crises and Disasters: A Parents Guide to Talking with Children of All Ages.* 2015
 - COVID related resources

Additional Resources

- Teenagers
 - Silver and Silver. *My Parent has Cancer and It Really Sucks*. Sourcebooks. 2013.
- Young Children
 - Arthur (English and Spanish) LiveStrong
 - http://www-tc.pbskids.org/arthur/health/pdf/arthur_cancer_english.pdf
- Parents
 - Rauch and Muriel. *Raising an Emotionally Healthy Child When a Parent is Sick*. McGraw-Hill. 2006.
 - Cancer.net Patient education resources

For Clinicians

- www.mghpact.org
- MGH Psychiatry Academy Online Course, CME/CE 10 hours. Didactic lectures. Simulated interviews. Psychoeducational handouts.
- Timing for the next run of this course TBD