

# THERAPEUTIC WORK WITH CHILDREN AND ADOLESCENTS WHEN A PARENT IS TERMINALLY ILL

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April 8, 2011

# Building Blocks

- ◆ Kids are great information seekers, lousy interpreters
- ◆ Magical thinking shapes how children understand illness
- ◆ Children are aware of seriousness of a condition & can identify parental distress.
- ◆ Children are usually eager to talk about illness, but take their lead from grown-ups around them.
- ◆ Family may not have a language to discuss illness & its emotional impact.
- ◆ Children try to protect their parents and remain

# Overarching Goal

Balance family resources and energies to manage illness progression and grief work while keeping children on track developmentally.

# Issues for Assessment

- ◆ Social history of child & family before diagnosis
  - / Role of ill person and the child(ren) in family life
  - / Coping style and history of trauma
  - / History of unresolved mourning
  - / Level of family cohesion –normative expectations vs. illness requirements.
- ◆ Nature of the Illness
  - / Timing of illness (timely, untimely)
  - / Concurrence of multiple stressors
  - / Illness/loss during major transitions
  - / Family & community beliefs about illness and healing
- ◆ Family & Community Resources

# Infant/Toddler Years

## *Primary tasks:* empathy & emotional attunement

- / Communicate needs, frustration & happiness
- / Begin language development
- / Develop coordination: Sit, stand, walk, manipulate objects
- / Recognize self as separate person
- / Develop trust with caretakers
- / Overcome fear of new situation

## *When parents of infants are sick/dying*

- / Trust in attachment figures compromised
- / Perceptions of situations cannot be verbalized
- / Kids worry about dying themselves
- / Strong reactions to separations from caregivers

# Early Childhood, 3-6 yrs.

Primary Task: Growing understanding of Interdependence

- ◆ *Emotional Development*
  - / Emotional regulation and control
- ◆ *Cognitive Development*
  - / Awareness of gender, race, ability, disability
  - / Rule-bound
- ◆ *Social Development*
  - / Enhanced communication
  - / Early enduring friendships: trust, sharing
  - / Cooperative, dramatic, fantasy play

# Parental Loss in Early Childhood

When parents of young kids are sick/dying

- / Experience anticipatory anxiety “What if’s”
- / Magical thinking
- / Feel abandoned by both parents/caregivers
- / May feel guilty for worrying parents
- / Initiative may be inhibited
- / Attempt to protect parents by maintaining “hope”

# Interventions in Early Childhood

- ◆ *Clinical Goals*
  - / Enhance emotional language
  - / Provide clear & appropriate information
  - / Build on self-esteem and attachments
  - / Support consistency in family life
- ◆ *Interventions for young children*
  - / Feeling Faces for Scary Places
  - / Feeling Cards
  - / Inside/Outside Feelings (masks)
  - / Bibliotherapy

# Middle Childhood: 6-11 yrs

*Primary task: Moral development, logic*

- / *Emotional Development*

- / Increased empathy

- / Increased understanding of gender, culture, ability

- / *Cognitive Development*

- / Develop appreciation for difference

- / Math, reading, writing, following rules & games, coordination & motor skills.

- / *Social Development*

- / IMPORTANCE OF SCHOOL

# Parental Loss in Middle Childhood

*When parents of school-aged kids are sick/dying:*

- / Trouble concentrating at school, may confide in teachers, neighbors, community members
- / Worry about parents dying while they are away
- / Fantasy of return to former life
- / Loss of childhood innocence, overburdened
- / Desire to be home with dying parent, less play
- / Somatization to mirror parent

# Clinical Goals for School Aged Kids

- ◆ *FOR KIDS:*

- / Provide information!
- / Prepare the child for medical emergencies
- / Acknowledge fears, anticipatory loss

- ◆ *FOR PARENTS/FAMILIES:*

- / Build a support network for the family
- / Encourage “away” time
- / Give kids choices
- / Protect “normal” time
- / Establish a frame for addressing concerns: family meetings
- / Model emotional expression
- / Do not rely on children to ask questions - encourage parents to bring it up!

# Interventions for School-Aged Kids

- ◆ Possible/Impossible (puppets)
- ◆ Fish Families
- ◆ Spin me a Yarn (group work)
- ◆ Letter writing
- ◆ Cancer Alphabet
- ◆ Book making

# Puberty: *Finding one's voice*

## ◆ *Physical Development*

- / Awareness & development of sexuality
- / Cope with dramatic changes in body

## ◆ *Emotional Development*

- / Increased development of emotional competence
- / Ability to assert oneself

## ◆ *Cognitive/Moral Development*

- / Moral understanding & recognition of injustices
- / Develop ability to think conceptually

## ◆ *Social Development*

- / Ability to handle complex relationships & situations.
- / Increased understanding of self in relation.

# Adolescence: Identity Development

- ◆ *Physical Development*
  - / Increased awareness about sexuality & control over impulses.
- ◆ *Emotional Development*
  - / Development of physical and emotional intimacy
- ◆ *Cognitive/Moral Development: Abstract Thought*
  - / Increased self management
  - / Increased philosophy of life
  - / Moral & spiritual identity
- ◆ *Social Development*
  - / Balance care for self & for others
  - / Negotiate peer pressure to conform

# Parental Loss in Puberty/Adolescence

## *When Parents of Preteens & Adolescents are dying*

- / Teens drawn back into family system
- / School can provide respite
- / Experience anticipatory grief
- / Greater understanding of how purpose, beliefs and future goals impacted by parental loss

## *Clinical Goals with Preteens & Adolescents*

- / Normalize, validate self worth
- / Maintain family structure, rules. Watch for drug use.
- / Give ample treatment & prognosis information promptly
- / Facilitate discussion of feelings, room for normative volatility

# Working with surviving parents

## GRIEF IS CHRONIC & LIFE-LONG FOR PARENTALLY BEREAVED KIDS.

- / Early parental loss linked to dis-regulated cortisol response, depression in adulthood.
- ◆ Parent may be compromised by their own grief. Must grieve loss to be available to bereaved child.
- ◆ Anticipated death more challenging, exhausting than sudden death – losing both parents, change in rituals, anticipatory loss.

*Most powerful predictor of child's successful adaptation to parental loss is presence of nurturing parent who models appropriate grief and maintains a stable environment.*

# Tasks for child-centered parenting

(SALDINGER, PORTERFIELD, CAIN, 2004; PSYCHIATRY)

1. Communicating information about illness and death
2. Communicating about feelings
3. Maintaining a stable environment
4. Exposure to dying/deceased parent
5. Participation in funeral/memorial service
6. Responsiveness to children's loss-related needs.
7. Obtaining support for children
8. Facilitating continued attachment to dying parent
9. Meaning-making with child

# Parenting tasks as spouse is dying

## COMMUNICATING INFORMATION ABOUT ILLNESS & DEATH

- / Providing honest, understandable & age-appropriate information
- / Encouraging parents to be thoughtful about what & how they share info.

## COMMUNICATING ABOUT FEELINGS

- / Parents must express their own feelings to facilitate child's experience.
- / Distinguish emotional from informational communication.

## MAINTAINING A STABLE ENVIRONMENT

- / Family routines maintained/recreated to support safety & confidence.

# Parenting tasks at the time of death

## EXPOSURE TO DYING/DECEASED PARENT

- / Consideration of child's wishes & ability to tolerate sight of ill/dead parent.
- / Parent needs to protect child – Child needs to say goodbye.

## PARTICIPATION IN FUNERAL/MEMORIAL SERVICE

- / Makes the death a reality, brings closure, draws in supportive resources.
- / Parents should be encouraged to consider child's needs and wishes.

## AWARE & RESPONSIVE TO CHILDREN'S LOSS-RELATED NEEDS

- / Parents must be coached to recognize idiosyncratic ways children process death & experience grief.

# Parenting tasks for resuming family life

## OBTAINING SUPPORT FOR CHILDREN

- / Parents must adapt to becoming a single parent, need their own support.
- / Parents should identify formal and informal sources to support continuity and expression.

## MEANING-MAKING WITH CHILD

- / Evolves with child's cognitive & moral capacity

## FACILITATING CONTINUED ATTACHMENT TO DYING PARENT

- / Relationship with deceased parent serves as anchor, resource for children through their lives, supports identity development with normative differentiation, provides solace, continued guidance.
- / Support relationships with adults who knew parent & child