

The Forgotten Child

The Psychosocial Impact Of Having A
Sibling With A Chronic Illness or Condition



USC University of
Southern California

Stephanie Marcy, Ph.D.
Pediatric Psychologist
Clinical Associate Professor of Pediatrics
Children's Hospital Los Angeles
USC Keck School of Medicine

Disclosures

- Nothing to disclose

Permissions

- Patients and families participated in the interviews that will be shared for this and other lectures knowingly and willingly. The discussions were considered to be helpful to them as part of their current clinical care. They were aware that they could refuse participation, as well as request to terminate video taping whenever they wanted without any impact on their continuing clinical relationship.

Sibling Relationships

- ◎ Interpersonal bonding
- ◎ Context for social skills development
- ◎ Enable Prosocial behaviors
 - Healthy Competition
 - Cooperation
 - Sharing
- ◎ Loyalty and trust
- ◎ Shared Experiences (good and bad)
- ◎ Bonding

Nonfinite Grief

- Expansion from focus on grieving and psychosocial problems following death of ill sibling, to include coping and adjustment to stressors during chronic illness
- Grieving for a different type of loss

Research: Some Lack of Convergence

- ⦿ Increased responsibility at home
- ⦿ Decreased participation in social and extracurricular activities
- ⦿ School struggles
- ⦿ Disrupted peer relationships
- ⦿ Increased risk for adjustment symptoms
 - Anxious, depressive, behavioral symptoms
 - Not consistent findings
 - May be sub-clinical

The Healthy Sibling's Experience:

- ◉ Anger
- ◉ Guilt
- ◉ Fear
- ◉ Embarrassment
- ◉ Grief
- ◉ Alienation
- ◉ Loneliness
- ◉ Insecurity
- ◉ Depression
- ◉ Anxiety
- ◉ Hopelessness
- ◉ External locus of control
- ◉ Low self-esteem
- ◉ Separation anxiety
- ◉ Lower quality of life
- ◉ Overburdened
- ◉ Confusion
- ◉ Ambivalence

Guilt....

- ⦿ For being healthy (i.e., being spared)
- ⦿ For bad thoughts about sibling
- ⦿ For feeling jealous
- ⦿ For fighting with sibling
- ⦿ For causing illness
- ⦿ For upsetting parents
- ⦿ For doing anything that adds to parent's stress

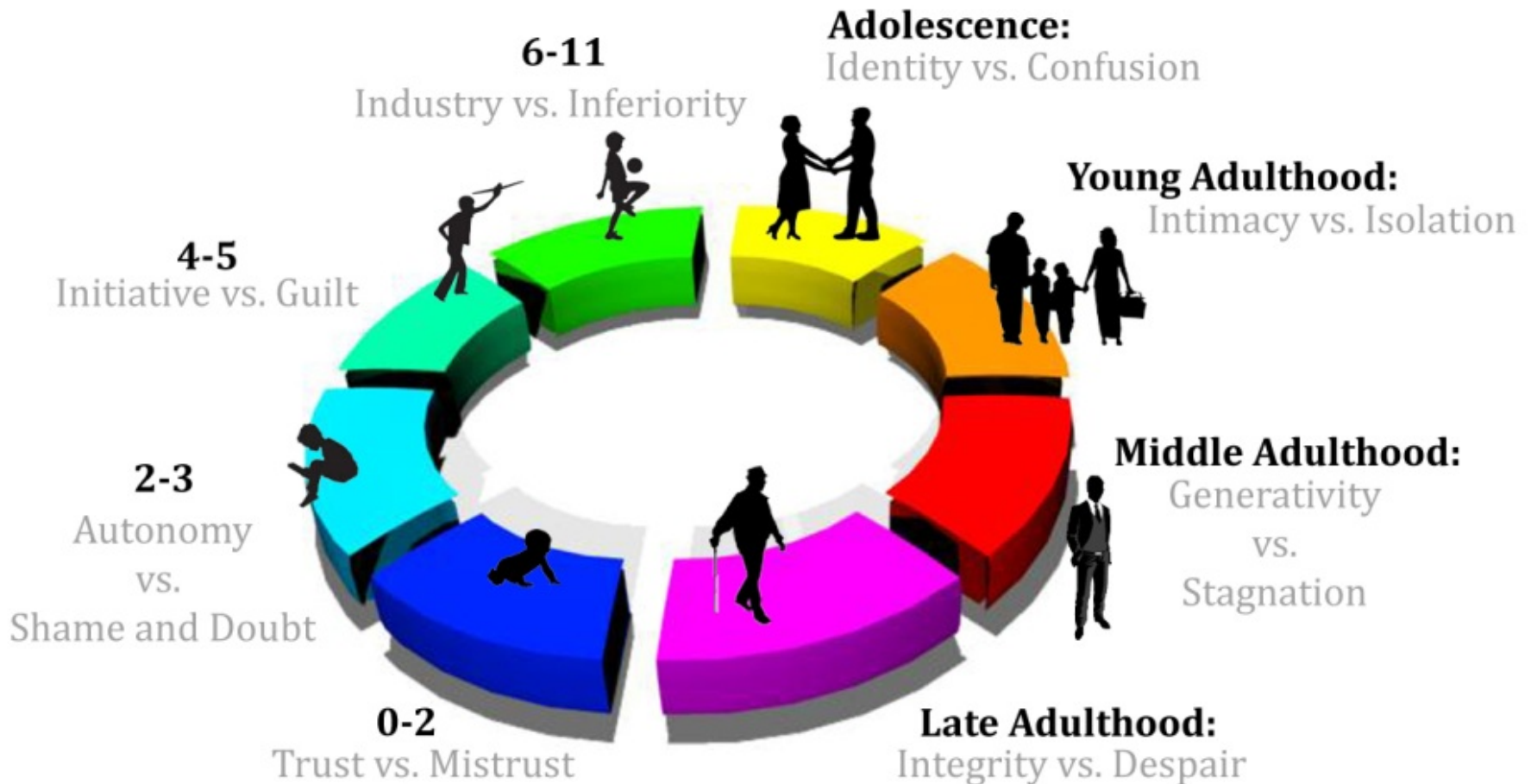
Traumatic Experiences

- ⦿ Separation from parent(s)
- ⦿ Fear of sibling dying
- ⦿ Fear of dying themselves
- ⦿ Observing/witnessing sibling in stages of care or illness
- ⦿ Observing parental distress
- ⦿ Many experience sx of traumatic stress
 - Intrusive thoughts
 - Avoidance
 - Hyperarousal/hypervigilance

Compensatory Behaviors

- Heightened Responsibility
- Perfectionistic (“The Perfect Child”)
- Protective of affected sibling(s)
- Advocate for sibling or for sibling’s cause
- Increased preoccupation with own health

Developmental Perspective



Infancy

- ◎ Trust
- ◎ Parental Co-regulation
- ◎ Nurturance
- ◎ Establishing healthy attachment

Challenges When Sick Sib

- ⦿ Unavailability of parent
- ⦿ Separations
- ⦿ Multiple caregivers
- ⦿ Decreased/inconsistent attachment behaviors
 - Cuddling
 - Holding
 - Soothing
 - Bedtime routine
 - Interruption/cessation of nursing

Toddlers

- ⦿ Autonomy
- ⦿ Self-Control
- ⦿ Secure attachment base
- ⦿ Psychological and physical independence

Challenges

- Parental absence
- Frequent separations
- Lack of consistent routine
- Perceived parental distress
- Child lacks cognitive sophistication to understand reason or duration for separations
- Security challenged
- Missed opportunities to test and gain mastery

Preschoolers

- Initiative
- Magical thinking
- Egocentric
- Omnipotent
- Correlation = Causation
- Curious and inquisitive (“why?”)

Challenges

- ⦿ Magical thinking – void of logic
 - Thoughts cause events to occur
 - Guilt
 - Fear of punishment
 - Shame
- ⦿ Lack or loss of routine
- ⦿ Limited social events & opportunities
- ⦿ Diminished self-esteem

School Age

- ⦿ Accomplishment/Industry
- ⦿ Cooperation
- ⦿ Competition
- ⦿ Peer identification and increased influence
- ⦿ Desire to fit in and “belong” to a peer group

Challenges

- ⦿ Limited participation in social activities
- ⦿ Unable to commit to sports schedule
- ⦿ Social alienation
- ⦿ “Different”
- ⦿ Loneliness
- ⦿ Isolation
- ⦿ Guilt/responsibility persist

Adolescents

- Identity
- Role development
- Independence
- Strong peer group influence
- Healthy separation from parents

Challenges

- Decreased social activities
- Social isolation
- Loneliness
- Anger
- Defiance
- Delayed individuation due to guilt and/or sense of responsibility to sibling & family

GROWING UP TOO FAST VS. DELAYED SEPARATION AND INDEPENDENCE



Precocious maturity

- ◎ Parentified
- ◎ “The Little Mom”
- ◎ Unrealistic expectations of self
- ◎ Implicit expectations from others
- ◎ Achieve early self-sufficiency

Older Siblings

- Delayed independence from family
- Heightened sense of responsibility
- Leaving home for “good reason” vs. selfish ones
- Guilt over “abandonment”
- Stay close “just in case”
- Parental ambivalence (altruism vs. own needs)

◎ Some evidence to suggest that parents not accurate reporters of healthy sibling's symptoms. Why?

- Internalizing symptoms less obvious
- Child hiding them
- Parent doesn't have "luxury" to worry about healthy child
- Parental guilt – too afraid to ask
- Parent too dysregulated him/herself

Research Trends For Protective Factors

- Family Cohesion (vs. enmeshment)
- Perceived Social Support
- Higher SES
- Positive outlook on illness
- Gender (male)
- Age (older)
- Duration of illness (adjust with time)
- Visibility of illness/disability

Primary Care Setting



Acknowledge and Listen

- Address healthy child by name
- Ask them about themselves
- Treat them like an important person
- Acknowledge their roll in the family system
- Ask them questions about the affected sibling
- If you can, give them a book or toy, too

What to look for

- Regression
- Sleep disturbance
- Change in appetite/eating
- Somatic complaints
- Anxiety
- Withdrawal
- Irritability
- Avoidance
- Anger/Aggression
- Overreacting
- Academic decline



What Can Help

- ⦿ Talk to the healthy sibling
- ⦿ Allow for questions and open discussion
- ⦿ Affiliation with others going through the same thing
- ⦿ Facilitate sibling understanding of illness, through explanation at developmentally appropriate level
- ⦿ Let the siblings help in care by giving them specific “jobs” (delicate balance)
- ⦿ Facilitate family cohesion
- ⦿ Give sibs permission to be children and not second parents

- ⦿ Encourage parents to make “appointments” for special time with healthy child
- ⦿ If feasible, have parent schedule medical visits for healthy child separately from ill child
- ⦿ Help family to enhance support and/or implement accommodations in school
- ⦿ Help healthy siblings figure out and practice what to say to others to decrease avoidance or social withdrawal
- ⦿ Encourage some semblance of routine
- ⦿ Discuss and plan for care for affected sibling for later in life
- ⦿ Siblings only events

Is It All Bad?

- More Compassionate
- Helpful
- More Patient
- Responsible
- Resilient
- High Achievers
- Solve problems on their own
- “It’s an odd gift to realize at a young age that you’re not the center of the universe.” (NPR News 11/28/10)

Resources

- ◎ <https://www.siblingsupport.org/>
 - “Sib shops”
- ◎ <http://www.p2pusa.org/p2pusa/sitepages/p2p-home.aspx>
 - Parent 2 Parent USA – special needs
- ◎ <https://www.eamf.org/>
 - “Shine on Siblings”
- ◎ <http://handtohold.org/support/sibling-support/>
 - For NICU families