

# COPING AND SPIRITUALITY IN PEDIATRIC CANCER PATIENTS AND THEIR FAMILIES



# Agenda

- Pediatric cancer overview
  - ▣ Statistics
  - ▣ Psychosocial outcomes
- Coping with pediatric cancer
  - ▣ Models/ classifications
  - ▣ Research findings
- Spiritual & religious coping
  - ▣ Conceptualizations
  - ▣ Functions
  - ▣ Challenges & future directions



# Pediatric Cancer

- 10,700 children under age of 15 were diagnosed with cancer in 2010 (US alone)
- 80% survival rate
- Complex and persistent challenges:
  - ▣ Demanding medical regimens
  - ▣ Painful medical procedures
  - ▣ Aversive treatment side effects
  - ▣ Disruption of daily routines/  
social and family roles
  - ▣ Threat of death



# Common Cancer-related Stressors

Hildenbrand et al., 2011

	<b>Child Report</b>	<b>Parent Report</b>
<b>Cancer treatment and side effects</b>	Pain and/or other side effects Hair loss Needle sticks/ port access/ spinal taps Taking medicine Hospital visits Staying overnight at the hospital Sleep difficulties	Pain and/or other side effects Hair loss Needle sticks/ port access/ spinal taps Taking medicine Hospital visits Staying overnight at the hospital
<b>Distressing emotional reactions</b>	Feeling scared or nervous Feelings of uncertainty Fear of death Thinking about being sick Not wanting to discuss cancer	Feeling scared or nervous Feelings of uncertainty Fear of death Feeling sad Questioning: 'Why me?'
<b>Disruption in daily routines and activities</b>	Wanting to be normal Missing home/ family/ friends Missing school Being restricted to home	Wanting to be normal Missing home/ family/ friends Missing school Adjusting to changes in routines
<b>Social/ peer group challenges</b>		Peer bullying/ teasing Difficulty maintaining relationships

# Psychosocial Outcomes

- Psychosocial sequelae
  - ▣ Distress/ anxiety/ irritability
  - ▣ Depression
  - ▣ Posttraumatic stress
  - ▣ Impaired family functioning
- Negative impact on functional outcomes:
  - ▣ QOL/ psychological well-being
  - ▣ Adherence
  - ▣ School performance

# Coping with Pediatric Cancer

- “What children actually do (their profile of emotional, cognitive, and behavioral responses) in dealing with specific difficulties” (Skinner & Zimmer-Gembeck, 2007).
- Models/ Classifications
  - ▣ Approach-oriented vs. avoidance-oriented coping
  - ▣ Problem-focused vs. emotion-focused coping
- Influence of coping on key outcomes:
  - ▣ Quality of life
  - ▣ Adjustment to cancer

# Parent Coping Assistance

- Parents influence child's appraisal of stressors & subsequent coping responses
- Can affect child coping via:
  - ▣ Coaching— direct instruction/ suggestions
  - ▣ Modeling— child observes parent behavior
  - ▣ General family context
- Child adjustment
  - ▣ Facilitated when parents encourage approach coping strategies
    - E.g. adopting a hopeful outlook and promoting family cooperation and support

# Spiritual and Religious Coping

- “Use of cognitive and behavioral techniques, in the face of stressful life events, that arise out of one’s religion or spirituality” (Tix & Fraser, 1998)
- Conceptualizations
  - ▣ Often conceived as emotion-focused
  - ▣ Can also have cognitive and behavioral components
  - ▣ Unique coping dimension vs. form of another dimension?
- Bi-directional influences
  - ▣ Spirituality/ religion  illness experience

# Spiritual Coping: Cancer

- Among the most frequently reported by cancer patients
- Functions
  - ▣ Emotional comfort and hope
  - ▣ Maintain self-esteem
  - ▣ Sense of meaning and purpose
  - ▣ Congregational/ social support
  - ▣ Reframing stressful events
  - ▣ Provide sense of control



# Spiritual Coping: Pediatric Cancer

- Qualitative interviews with children with cancer and their parents (N = 30)

## Sample Comments: Parents

[To help my child cope with cancer, I] basically just keep faith in God and pray.

[To help my child cope,] I just had to let go and let God... because basically there's nothing I can do and I don't want to keep getting my hopes up high, my sons hopes up high. We just have to deal with it day by day. It's not easy, it's not easy at all... And it's hard to watch him go through this and I just ask God to give him his childhood back.

Last time around she did a lot of praying... we spend a lot of time down the chapel, that seems to help make her feel better. She was physically sick, but you know she wanted to pray. So we sat and prayed for a while... [the chapel] seems to give her a nice, secure, calming place to go.

Since we are Christians, we pray a lot. Everything we are doing, we put God in it. We invite God to it and I think that's what makes it easy. The people in our church, I have a lot of support... If I told them we need them right now, somebody will come. Everybody is so up to do whatever helps him best and it's become normal, like its normal.

# Spiritual Coping: Pediatric Cancer

- How I Coped Under Pressure Scale (HICUPS)
  - ▣ Do these things to make yourself feel better about having cancer or about cancer treatment
- Parent Socialization of Coping Questionnaire (PSCQ)
  - ▣ Encourage/discourage your child to use these strategies to deal with his/her cancer diagnosis and treatment

Religious Coping Subscale Items	% Endorsed	
	Children	Parents
Prayed more than usual	50.0	29.4
Asked God for help	60.0	5.9
Prayed for comfort	57.2	23.5
Put trust in God	71.4	17.7
≥ 1 religious coping item	93.3	58.8

# Impact of Spiritual Coping

- Influence of spirituality on key outcomes:
  - ▣ Illness adjustment
  - ▣ Well-being/ Quality of Life
- Other outcomes/ indices:
  - ▣ Children's understanding of cancer
  - ▣ Connectedness to family



# Challenges

- Scarcity of research
  - ▣ Particularly in pediatric populations
- Conceptualization
  - ▣ Varied definitions
  - ▣ Unique coping dimension vs. form of another dimension
  - ▣ Developmental considerations
  - ▣ Cultural issues
- Methodology
  - ▣ Measurement
  - ▣ Study design
  - ▣ Time of assessment/ stage of disease

# Future Directions

- Dynamic, multidimensional conceptualization
  - ▣ Cognitions and behaviors
- Measurement
  - ▣ Developed specifically to assess spiritual/ religious coping
  - ▣ Measures with strong theoretical basis
  - ▣ Mixed-methods assessments
- Study design
  - ▣ Longitudinal
  - ▣ Consider disease stage & length of illness
- Pathways by which spiritual coping influences outcome variables

# Discussion

- Does spiritual/ religious coping represent a unique coping dimension?
- What are the ways by which spiritual/ religious coping can influence the pediatric cancer experience (and vice versa)?
  - ▣ Positive impact
  - ▣ Potentially negative effects
- How can spiritual and religious coping be incorporated into existing interventions to increase QOL and adjustment in pediatric cancer patients?

# Thank you!

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