

ICEOS 2009

**The Psychosocial Impact
of Multiple Surgeries**

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Disclosures: RMC

- Royalties from Synthes Spine for the VEPTR device
- Non-compensated volunteer member Medical Advisory Board SpineForm Co.
- Medical Advisory Committee member National Organization of Rare Disorders (NORD)
- Grants
 - NORD and FDA Office Orphan Product development
- Provide advocacy for companies or inventors trying to develop safe and effective devices for children

Repetitive Surgeries

- Growing Rods
- VEPTR
- Complex Limb Lengthening
- VP Shunts

Repetitive Surgeries

- Growing Rods
- VEPTR
 - Major Case (Implant)
 - Expansion of devices every 6 months
 - Endpoint , fusion at age 10 yrs to skeletal maturity ?

The Realities of Repetitive Surgeries

Peri-Operative Stress on Families

- Parents
 - Illness/Procedure/Complications
 - Financial Burden of Travel
- Children
 - Illness/Procedure/Separation

San Antonio Experience

Multiple VEPTR Surgeries

1989-2008

- Episodes of pre-operative panic attacks in surgical holding areas by some patients
 - Intense crying, agitation
- Years of prior surgeries without problem
 - Problem seemed to start age 8 to 9 yrs

“Repetitive Surgery Syndrome”



“Repetitive Surgery Syndrome”

Carlos Tello first noted the emotional toll of multiple surgeries on children undergoing growing rod treatment

-1994, Orthop Clin N. Am

What's the clinical cost?

- Pre-operative Disruption
- Compliance with post-operative instructions
- Long term PTSD?
(Posttraumatic Stress Disorder)

Posttraumatic Stress Disorder

- Most commonly seen in combat veterans
- Since 1994, recognized as a sequellae of chronic medical disease in adults and children
 - Cancer, burns, heart disease, organ transplantation, trauma, others

Can be seen after both acute (Type I) or chronic (Type II) traumatic experiences

Symptoms of Pediatric Posttraumatic Stress Disorder

- Disorganized , agitated behavior
- Recurrent or distressing thoughts
- Repetitive play
- Nightmares
- Sleep disturbance
- Difficulty concentrating

Posttraumatic Stress Disorder

- Clinically significant problem?
 - Functional Impairment?
 - Clinically important stress?

-Stuber et al., Child Adol Psych Clin N AM, 2003

Posttraumatic Stress Disorder

Roles

- Parents
 - Witnesses
 - Decision makers/participants in treatment

Posttraumatic Stress Disorder

Roles

- Care givers (physicians, others)
 - Decision makers/participants in treatment
 - Cause the trauma

Posttraumatic Stress Disorder

Roles

- The children
 - May view caregivers as “perpetrators”
 - May view parents also as accessory “perpetrators”
 - When do children understand the concept of parent “tough love” ?

Pediatric Posttraumatic Stress Disorder

- Children may view medical procedures and treatment as “trauma” inflicted by caregivers with support of the parents, not recognizing the necessity for control of disease

Pediatric Posttraumatic Stress Disorder

- 40 pts, elective surgery
 - PTSD lasted about one month after surgery
 - Significant correlation between development of pt PTSD and parent anxiety

-G Ben-Amitay et al., J Ped Child Health, 2006

Pediatric Posttraumatic Stress Disorder

- Girls are more at risk
- Parents: 24-40 % of those with children with cancer had PTSD

-Wintgens, et al, Can J Psych, 1997

Pediatric Posttraumatic Stress Disorder

- 400 pts with Orthopedic Injuries
- 33% with PTSD at 12 month f/u

-Sanders, et al, JOT , 2005

Pediatric Posttraumatic Stress Disorder

- Solid Organ Transplantation
- 30% patients report symptoms twice / month
- 13 % twice/ month

Factors governing sequellae of Posttraumatic Stress Disorder

- 43 Cardiac Surgery pts
- 12 % PTSD
 - ICU stay > 48 hrs increased rate of PTSD

-Connoly et al., J Ped, 2003

Pediatric Posttraumatic Stress Disorder

- Cancer Survivors (age 8-20 yrs)
 - 2.6% Severe PTSD
 - 12.1% Moderate PTSD
- Normals
 - 3.4% Severe PTSD
 - 12.3% Moderate PTSD

-Stuber et al., Child Adol Psych Clin N AM, 1998

Factors governing sequellae of Posttraumatic Stress Disorder

- Unknown or shortened life expectancy
- Uncertainty about the stresses
 - Time of diagnosis
 - Procedures
 - Disability due to effects of the disease
- Medical dysfunction vrs PTSD dysfunction

-Stuber et al., Child Adol Psych Clin N AM, 2003

Sequellae of Posttraumatic Stress Disorder

- 51 Cancer survivors
- 22% PTSD
 - None of PTSD pts married
 - 23% of non-PTSD pts married
- Survivors with PTSD
 - Avoidance behavior
 - Poor quality of life
 - Social functioning affected
 - Emotional well-being affected

Posttraumatic Stress Disorder

- Intervention
 - Treatment for PTSD can improve medical adherence

-Shemesh, et al., Pediatrics 2000

Posttraumatic Stress Disorder

Important Issues

- Understand the problem from the family side
- Sedation/ pain management without loss of control
- Treatment and Intervention
- More Research!

Thank
You!

