Supporting Families and Children in Hospitals

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Topics

- Psychosocial aspect of patient care
- Child Life department
Patients’ Journeys

• We see patients at their worst and at their best

• From emergency care to diagnosis, through treatment, to the long term care

• It is a long journey which is shared between patient and health care practitioner

• Chronic illnesses
  • prolonged in duration
  • does not often resolve spontaneously
  • rarely cured completely
Children and Youth

• Children with chronic illnesses are at risk of developing mental health problems
  • Physical and lifestyle modifications
  • Restricted participation in sports and school activities

• These factors may limit spontaneity, create challenges for social relationships, and generate concerns about the future
Parents and Siblings

• Increased levels of stress due to intensified demands of their care and support role
• Financial pressures
• Strains on their marriages and relationships
  • Loss of child-divorce
• Siblings are at increased risk of:
  • Anxiety and intense emotions
  • Experience confusion and difficulty communicating about the illness
  • May feel overlooked
  • And can experience negative changes to family and social functioning as a result of their sibling’s illness
Resiliency

• Some families are able to positively manage the impacts of the illness on their lives to
  • Build stronger relationships
  • Learn coping skills
  • Draw on their strengths
  • Refocusing priorities
  • Recognizing opportunities and adapting to the situation so they achieve a sense of functioning just as well as ‘healthy’ families
  • Dynamic process-work through their emotions and feelings
“I said: what about my eyes?  
He said: Keep them on the road.

I said: What about my passion?  
He said: Keep it burning.

I said: What about my heart?  
He said: Tell me what you hold inside it?

I said: Pain and sorrow.  
He said: Stay with it. The wound is the place where the Light enters you.”  

Rumi
Basic Needs of the Families

- The need for information
- The need for reassurance and support
- The need to be near the patient
Patients consistently report informational and emotional needs that are unmet in their journeys (Sussman and Baldwin 2010)

The question then is how effectively do we address psychosocial care with our patients?

There are two important issues in the delivery of psychosocial care (Muriel et al 2009)

- Recognition of distress
- and the knowledge of available mental health resources
What is Psychosocial Care?

- Part of a holistic patient perspective
- Psychosocial care involves the culturally sensitive provision of psychological, social and spiritual care/support
- Goal is to work with the children and families to reduce stress and support them through their journeys
Why provision of Psychosocial Care is Important?

• The provision of good psychosocial care has been shown to be beneficial for patients by reducing both psychological distress and physical symptoms
  • Increasing quality of life and resiliency
  • Enhancing coping and reducing levels of discomfort with a consequent reduction on demands for hospital resources
    (Ellis et al 2006; Carlson and Bultz 2003)
Pediatric Psychosocial Care Standards

• Systematic assessment
  • Youth and their family members for psychosocial health care needs at the time of admission

• Provide psychoeducation, information, and anticipatory guidance related to disease, treatment, acute and long-term effects, hospitalization, and procedures

• Yearly psychosocial screening for children with chronic illnesses
  • Educational and/or vocational progress
  • Social and relationship difficulties
  • Distress, anxiety, and depression
• Easy access to child and adolescent psychiatry

• Assessment of risk for financial hardship of the families
  • Single parent status, distance from treating center, anticipated long/intense treatment protocol, and parental employment status
  • Negative implications for quality of life
  • Parental emotional health
    • Parents and caregivers of children with chronic illnesses should have routine assessment of their mental health needs
    • Siblings of children with chronic illnesses should be provided with appropriate supportive services
Psychosocial Care in Pediatric Health care settings

THE BIOPSYCHOSOCIAL MODEL OF HEALTH

BIOLOGICAL
- Genetic vulnerabilities
- Drug Effects
- Temperament
- IQ

MENTAL HEALTH
- Family circumstance
- Peers
- Family relationships
- Self-esteem
- Social skills
- Coping skills

PSYCHOLOGICAL
- School

PHYSICAL HEALTH
Child Life Services in Health Care setting

• Department recognizes that illness, injury, and hospitalization are stressful events

• The department aims to provide expert interventions based in the modalities of therapeutic play, creative expression, and developmentally appropriate preparation and education

• Care is individualized, evidence-based, family-centered and culturally-sensitive, with the aim to promote positive coping and well-being.
Chronic or long-term illness.
New diagnosis
Before, during and/or after procedures
Extended length of stay; acute or chronic pain; frequent admissions
Experiencing grief/loss; low social supports
Those having difficulties coping and/or exhibiting concerning behaviors

Child Life Services can help with...
Additional Interventions provided by Child Life Services include:

• Explanation of medical procedures and education around illness processes.
• Play interventions to lessen fear and anxiety
  • Medical play opportunities to help give children a sense of mastery and control in a threatening environment
  • Developmental play opportunities to support typical cognitive, physical, and social-emotional development while hospitalized
• Teaching of relaxation and coping skills before
• Accompaniment to procedures as a non-medical support person to provide distraction and coping techniques
thank you