Children and families living with chronic illness

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Prevalence

- 8% of higher number of children have a chronic illness (Hysing et al., 2007; survey of 9400 plus children in Norway)

- Increased risk of emotional and behavioral disorder in child with chronic illness (perhaps double the risk compared with general population)

- Direct effect of illness

- Events associated with physical illness
The CHILD with chronic illness
Common issues

- Being different from other children
- Why me?
- What is the child’s understanding of the illness?
- Infant. Does not understand the issue related to the illness. May be traumatized by treatments.
- Preschool child may feel the illness is a punishment for misbehavior, not being obedient, etc.
Common issues

- Magical beliefs about the illness, e.g. being "catchy", contagious, or eliminated magically
- School age child may resent "being different"
- Guilt and embarrassment with the illness and the required adjustments,
- Worries about school, absences, examinations, etc.
Common issues

• Adolescence
• More awareness of the illness, the future
• Contradiction between feelings of competence and unpredictability, dependency, need for treatments, vulnerability
• Financial concerns, school concerns
• Issues of finality and the future
Interventions with child

- Detecting degree of stress
- Anxiety
- Depression
- Posttraumatic phenomena
- Academic difficulties
- Other psychopathology
Understanding of illness

- Eliciting child’s theories of his or her illness
- Why am I sick?
- What will happen to me?
- Discussion of feelings about illness and treatments
- Discussion of accommodations, disturbances in routine, attitude toward school, medical staff, medications, etc.
Increase adherence to treatment

• Preparation of child to undergo procedures
  – E.g. venipunctures, hospitalization, bone marrow study, dialysis, chemotherapy, etc.

Emotional preparation for what will happen
Role play at appropriate age
Play with toys re. medical situations
Presence of parent or attachment figure during procedures
Adherence to treatment

- Simplify the regime
- Adjust to child’s already established routine
- Enhance understanding of treatment
- Honesty regarding side effects (or painful procedures)
- Help to cope with side effects of undesirable effects
Example. chemotherapy

- Aid to tolerate the after effects, e.g. nausea, vomiting, pain
- Guided imagery (nausea. Imaging a garden, liked odors, liked objects)
- Hypnosis or self hypnosis. “fresh odors” desired situations
- Debriefing regarding feelings
Dealing with painful procedures

- Preparation, Play, etc.
- Adequate anesthesia if possible
- Presence of attachment figure
- Biofeedback
- Hypnosis
- Self hypnosis
- Distraction
- Cognitive strategies
Dealing with emotional disturbance

- Depression, anxiety, etc.
- Cognitive and behavioral therapy strategies
- Play therapy strategies
- Psychodynamic strategies
- Psychopharmacology may be necessary, if possible
Common reactions in normal children

- Regression to previous stages of development
- E.g. after hospitalization
- "Baby talk", losing sphincter control, wanting a bottle, more frequent temper tantrums.
- More demanding, needy, clingy to parents, anxious
- These are common reactions to stress
Common complications of chronic illness

• Patterns of OVERPROTECTION or EMOTIONAL DISTANCE toward child.
• Often parents are extremely afraid and may overlook developmental needs of child for greater autonomy and competence.
• A parent may distance emotionally, immerse in work, unable to support child or spouse or other children.
Additional conditions

- Delirium. A child who is hospitalized.
- Stimulus deprivation, more often during the night.
- Effects of several medications, metabolic imbalance, etc.
- Child is thought to be “psychotic.”
- Cognitive symptoms of delirium.
SCHOOL issues and child with chronic illness
EFFECTS ON THE FAMILY
Common issues

• Learning about the diagnosis
• “receiving the news”
• Stages of reaction to the news:
  – Shock
  – Denial
  – Anger
  – Bargaining
  – Acceptance (not necessarily in that order, mixture of states)
Common issues

- Constant worry about the child
- “roller coaster” depending on course of illness
- Need to modify lifestyle in order to give diagnostic tests, repeated treatments, surgeries, hospitalizations, relapses
- Anger at child
- Compassion toward child
- Anger at health care treaters (doctors, nurses, etc.)
Issues of health care

- Worries about providing health care
- Financial issues involved
- Issues of “devastating illness”
- Dealing with insurance companies and making decisions. Appeals, denials, preauthorizations, etc
- Possible bankruptcy and despair
Effects on siblings

- Parents are preoccupied with ill child
- Siblings may experience worry about child
- Resentment toward ill child who takes so many resources from parents and others
- Parents may be temporarily absent in order to care for ill child
- Ambivalent feelings toward ill child
Interventions

- Help parents understand the nature of the condition
- Education about the medical illness
- Parent groups, self help groups with educational and mutual support purpose
- Assist medical staff to explain things and beign a bridge in communication
Interventions

- Parents have received information but they "were not listening"
- State of shock or disbelief
- After a certain word, parents may stop listening (e.g. leukemia, malignancy, tumor, failure, etc.)
- Repeated explanations with time for questions
- Mental health professional can help parents articulate questions
Interventions

• Parents need emotional support
• Parents may need practical help
• Expression of feelings regarding the illness and its after effects
• Conceptions regarding illness “whose fault is it”? 
Interventions. Marriage

- With Chronic Illness in child the marriage can
- STRENGTHEN or DETERIORATE
- Parents may need to join forces, support each other, cooperate, “strengths they did not know they had” or
- Parents may feel burdened, resentful, overloaded, blame each other, fight more, distance, stop talking “shut down”, etc.
Interventions

- Family therapy
- Address marital issues. Capitalize on strengths and “normalize” angry feelings, ameliorate feelings of guilt
- Address parent child issues
- Allow siblings to express their feelings, positive and negative
Interventions

- Siblings may show signs of stress
- Academic failure
- Negativistic or defiant attitude
- Emotional distance and withdrawal
- Anger toward the “sick child”
- Need for attention, closeness, even if negative or angry
The HEALTH CARE STAFF and the child with chronic illness
Common issues

- Becoming attached to the child with chronic illness
- Becoming emotionally involved with child
- Anger toward the biological parents of child, criticism, judgment, etc.
- Feelings of loss when the child relapses or dies
- Emotional distance toward the child or the parents
Staff dealing with parents

• Issues of “explaining things” to parents
• Use of language and technical explanations
• Parents may not be “listening” due to fear and shock
• Parents may displace anger toward health care staff
• Complaints about staff, doctors, nurses, etc. Of being insensitive, rushed, harsh, etc.
Interventions with staff

- Discussion of own feelings
- Stresses at work
- “blaming each other” in the health care team
- Being “too busy” to explain things to parents
- Seen as distant and cold
- A staff may be “overinvolved”
- Burn out, or frequent illness or absenteeism, or turn over of staff
Interventions with staff

- Issues of death of loss
- Issues of grieving, failure, blame
- Opportunities to express tensions,
- Informal conversations, curbside talks
- Balint groups. More formalized expression of feelings and tensions