FAMILY COPING WITH CHILDHOOD DISABILITY
AND CHRONIC ILLNESS

I. INTRODUCTION
  A. Psychologist by training; taught for past 20 years; now doing mostly research
  B. Longstanding research and clinical interest in family coping
    1. Family communication patterns - families of ped onc paients
    2. Family functioning - Mexican families, physically disabled
    3. Support groups - families, developmentally disabled
    4. Depression - Latina mothers of developmentally disabled

II. CHRONIC ILLNESS AND DISABILITY: A GROWING CHALLENGE
  A. Definition: * (SLIDE CHRONIC ILLNESS)
    1. A chronic illness is a health condition that lasts for more than 3 months in a year or that leads to continuous hospitalization for at least one month a year
    2. Also includes a proision of severity from mild to moderate and severe
  B. Improved mortality rates have led to concomitant increases in morbidity and chronicity
  C. Children
    1. 10-15% of children in the US have some chronic health impairment
    2. In US, major malformation occurs in 2 of every 100 births
    3. Common childhood chronic diseases include asthma, congenital heart disease, diabetes mellitus, cleft lip, spina bifida, sickle cell anemia, cystic fibrosis, leukemia, chronic renal failure, muscular dystrophy

III. DEFINITION OF COPING *(SLIDE - COPING DEFINITIONS)
  A. Coping refers to adaptation under difficult circumstances
  B. Coping refers to efforts to master conditions of harm, threat, or challenge when routine or automatic responses are not readily available

IV. PROPERTIES OF COPING * (SLIDE - PROPERTIES)
  A. Coping is a response to stress to restore equilibrium stress has disrupted
  B. Coping is a purposeful behavior, aimed at reestablishing the equilibrium that stress has disrupted
  C. Coping is a process - an evolving transaction between personal and situational characteristics
  D. Coping can be cognitive or behavior
  E. Coping is multifaceted and flexible

V. MODES OF COPING (SLIDE - MODES)
  A. Problem-focused
    1.Seeking information and support
    2. Taking problem-solving action
    3. Identifying alternative approaches

4. Goal is to eliminate or modify conditions giving rise to problem
5. Changes the situation

B. Emotion-focused
1. Secondary coping
2. When can't change outcome, change attitude about outcome
3. Goal is to keep emotional consequences of problems within manageable bounds
4. Changes the meaning of the situation, or
5. Manages the stress of the situation (relaxation, leisure activities)

C. Coping may employ strategies of approach or avoidance
1. Approach can solve problems, but create unnecessary worry; better when problems long-term
2. Avoidance may be useful short-term, allows regrouping; but risky long-term

VI. FACTORS INFLUENCING THE COPING RESPONSES

A. Characteristics of the medical condition * (SLIDE - CHARACTERISTICS)
1. Onset (acute or gradual)
2. Course (progressive - MD; constant - spina bifida; relapsing/episodic - asthma)
3. Incapacitation - degree; location; kind (mental vs. physical)
4. Outcome - fatal/not fatal
5. Severity per se not a predictor of parental response
6. Maternal coping, and to some extent family coping related more to general family factors and general chronic childhood illness variables than disease-specific factors

B. Premorbid personality - of patient, of family members (SLIDE * PERSONALITY RESOURCES)
1. Hardiness (commitment, challenge, control)
2. Optimism
   a. Opposite of helplessnes
   b. Explain bad things in situational (vs. stable), specific (vs. global), external (vs. internal) terms
   c. Better recovery from coronary artery bypass surgery
   d. Pts report fewer physical symptoms, greater well-being
3. Hope -
   a. agency - will to achieve goals
   b. associated with pathways (many ways of attaining goals)
4. Self-esteem

C. Social support

D. Financial and other external resources

E. Previous responses to crisis

F. Appraisal - * (SLIDE APPRAISAL)
1. Coping is interactive with appraisal of the stressor
   a. What event means to us
   b. Challenge; punishment; lesson; disaster
2. Appraisal may help to control the meaning of experience in a way that neutralizes its problematic character

G. Phase of family life cycle

VII. TYPES OF CHRONIC STRESSORS IN FAMILIES WITH CHILDREN WITH DISABILITIES AND CHRONIC ILLNESS * (SLIDE CHRONIC STRESSORS)

A. Stigmatized social interactions
B. Prolonged burden of care
C. Lack of information, need to master whole new body of knowledge
D. Inability to complete the grieving process
E. Father vs. mother stresses
F. Stresses associated with siblings, extended family

VIII. IMPACT OF DISABILITY ON FAMILY (SLIDE IMPACT OF DISABILITY)

A. Negative effects on individual family members
    1. Resentment, irritation, anger, anxiety, uncertainty
    2. Sense of burden
    3. Role readjustments
    4. High incidence of both psychosomatic and psychiatric illness, esp. despression(esp. mothers); diagnosis and treatment can lead to PTSD in both parents and child
    5. Sleep disturbances, increasing in smoking, anorexia
B. Negative systemic effects * (SLIDE FAMILY EFFECTS)
    1. Tremendous challenge to parents' sense of competence
    2. Lower family cohesion, expressiveness, higher conflict cmp. normals
    3. Maternal and child responses, highly interactive (link not directly between maternal and child symptoms, but between maternal sx, child appraisal, and then child sx)
    4. Marital dysfunction
    4. Siblings ignored
    5. Lack of communication (web of silence)
    6. Financial stressors
    7. Isolation from the larger society
    8. Infringements on leisure and work time
C. Positive effects
    1. Enrichment of family - greater family unity
    2. Personal growth and development
    3. Development of compassion and tolerance
    4. Association with other families of ill and disabled children

VIII. IMPACT ON MARITAL RELATIONSHIP

A. Not necessarily higher divorce rate, but higher stress, greater dysfunction
B. Mother enmeshed with affected child/father on periphery
C. Exacerbation of preexistent stressors
D. Common issues for fathers
    1. Fathers typically have less social support, less networking, less contact with professionals
    2. Needing to be the strong support
    3. Child as an achievement
    4. Escape through work

5. Difficulties in bonding with child
6. Lack of control over situation

IX. SIBLING ISSUES

A. Guilt, self-blame
B. Fear of contagion
C. Anger, jealousy
D. Somatization to receive attention
E. Compensatory perfectionism
F. Age-inappropriate parental behavior
G. Greater compassion, maturity

X. THE SOCIETAL CONTEXT OF FAMILY COPING * (SOCIETAL COPING)

A. Disability on a continuum of normalcy, illness on a continuum of health, but most people think of these as dichotomous (black and white thinking to create distance from feared event)
B. Spread effect
    1. Disability or illness takes over child's identity
    2. Entire family seen as having something wrong
C. Stigmatization
    1. Disability, serious illness seen as deviant, threatening
    2. Disliked, despised class
    3. Even children hold negative attitudes toward disability
D. Discomfort of nondisabled persons in presence of disabled or ill
    1. Reminds nondisabled of own vulnerability
    2. Underlying belief that handicap/illness represents punishment
    3. Fear of death
    4. Fear of loss of mastery and control
E. Comparisons of parents of disabled and nondisabled children (my research)
    1. Parents of nondisabled had much more negative views of disabled persons
        a. Evaluated them more negatively
        b. Saw them as more different from "normal" people
    2. Parents of nondisabled children engaged in significantly more personal blame attribution
    3. Disabled families had significantly less social support
    4. People who had not experienced disability tended to be glib about how they would cope
        a. Confident that having a disabled child would make them better persons
        b. Confident in their ability to cope in a take-charge manner
    5. Parents of disabled children more sober about its effects
        a. More likely to value most highly being able to share feelings
        b. Less confident of possibility of effecting instrumental change

XI. GOALS OF FAMILY COPING * (SLIDE GOALS OF FAMILY COPING)

A. General adaptational goals
    1. Restore equilibrium, homeostasis, family functioning
    2. Maintain efforts to control impact of stressor on family functioning
    3. Mediate stress for family members, maintain individual functioning
    4. Maintain family organization - integrity of family
    5. Promote member independence, self-esteem, positive outlook
    6. Maintain family bonds of coherence and unity
    7. Maintain and develop social supports, other resources

B. Illness-specific goals * (SLIDE - ILLNESS-SPECIFIC)
    1. Maintaining sense of membership in family for ill child
    2. Reorganizing family and reassigning roles
    3. Reestablishing an emotional baseline
        a. Keeping distress within manageable limits
        b. Mastery of resentful, self-accusatory, or other negative feelings
    4. Maintaining relationships with index child that afford some parental gratification while fulfilling child's physical and emotional needs
    5. Limiting impact of child's illness on family
    6. Developing expertise about child's condition

XII. COPING RESPONSES OF FAMILIES

A. Theoretical models of family coping * (SLIDE THEORETICAL MODEL)
    1. Many different models
    2. All agree on moderating variables
        a. Characteristics of specific event
            1. To what extent does it multiply effects of other preexisting stressors
            2. To what extent does it require coping resources
        b. Family appraisal in terms of family's relationships, status, and goals
        c. Resources available to family
        d. Past experiences with crisis situations
        e. Premorbid status of family - equilibrium of stressors/resources

B. Importance of recognizing role of STAGE THEORY in family coping * (SLIDE STAGE THEORY)
    1. Initial shock
    2. Acute reactions - denial, mobilization, guilt, blame
    3. Grief, chronic sorrow, anxiety, depression
    4. Anger and search for meaning
    5. Stabilization and normalization
    6. Reactivation of coping responses
    7. Reintegration, or chronic chaos, disorganization

C. Limitations of stage theory
    1. Descriptive, not explanatory, model - doesn't address why?
    2. May represent example of consensual thinking, rather than reality
    3. Restricts nature of "normal" coping responses available to family
    4. Some stages may occur simultaneously, or be omitted entirely

D. Discrepant coping
   1. When family members at different stages at different times
   2. Mothers tend to cope through emotional release, whereas fathers tend to cope practically or through withdrawal
   3. Leads to disagreements about how to interact, problem-solve
   4. May interrupt the grieving process
   5. May have positive aspect - provides more coping flexibility, increases family repertoire

E. Integration model * (SLIDE - INTEGRATIVE)
   1. Stressor interacts with premorbid state and current lifecycle stage to produce a series of Adaptive Tasks
      a. Knowledge task - understanding condition
      b. Personal task - dealing with personal emotions
      c. Interpersonal task - giving and receiving support
      d. Informational task - identifying appropriate treatment
      e. Social-integrative task - communicating diagnosis/prognosis to friends, neighbors, schools
   2. This sequence mediated by both internal and external Family Resources to produce an outcome

XIII. THE GRIEVING PROCESS AS A COPING RESPONSE * (SLIDE GRIEVING)

A. Mourning of shattered dreams, loss of the perfect child

B. Chronic sorrow
   1. Anger, despair, self-blame, anxiety, fear, depression
   2. Cyclical, not continuous, in response to different developmental stages

C. Tendency of society (and professionals) to pathologize grief, when in fact a normal response to a devastating situation

D. Grieving process may contain healing elements
   1. Completions - acceptance of loss, resolution
   2. Reformulations - enhanced sense of personal power; feelings of competency
   3. Transcendence - individual not bound by loss, able to change, grow

XIV. EFFECTIVE FAMILY COPING * (SLIDE EFFECTIVE COPING)

A. Acquiring and using social support
   1. Relationship between ss and effective adjustment
   2. Sense of sharing burden highly correlated with maternal adjustment
   3. Seeking social support most common coping strategy in response to physical health problems
   4. Negatives
      a. Must use, as well as have
      b. Can be smothering
      c. Fosters dependency
      d. Can focus people more on problems
      e. Self-reliance superior to social support in some studies

B. Communicating effectively inside and outside family

1. Being able to share feelings and fears
2. Being able to communicate assertively with professionals, make difficult decisions
3. Importance of clear communication with professionals, incl. explanation of condition, discussion of prognosis (altho 45% of sample said would prefer not to think about future), and emotional support
4. In terms of trauma theory, therapeutic value of discussing event

C. Developing instrumental skills
1. Problem-solving and information acquisition
2. Knowing how to interact effectively with health-care system

D. Maintaining a positive mental attitude
1. Optimism and hope
2. Humor

E. Positive reappraisal
1. Focusing on others' problems - could be worse
2. Recognition suffering is part of life
3. Moving problem to periphery of meaning

F. Focus on day to day, rather than worries about future

G. Ability to recognize and accept all aspects of child
1. Realistic acceptance
2. Emphasize child's strengths
3. Normalization of child's life
a. Minimizing impact of impairment
b. Functioning as child advocate

H. Supportive family environment -
1. Family cohesion assoc. with improved parental outcomes

XV. IDENTIFYING MEANING, whether through religious conviction or other experiences and beliefs

A. Inability to find meaning assoc. w/intense grief and depression
1. More disruptive, intrusive thoughts
2. Lower self-esteem, greater impairment in social function

B. Greater religious participation associated with increased perception of social support and greater meaning found in loss (SIDS)

C. Greater sense of meaning (incl. relig conviction) assoc with degreased depression and sense of burden (developmental delayed children)

XVI. COMMON NEGATIVE COPING STRATEGIES * (SLIDE NEGATIVE)

A. Blame (self and others)

B. Avoidance (chronic); denial
1. Of fact
2. Of implications
3. Of feelings

C. Self-denigration

D. Obsessive wishful thinking

E. Excessive self-control or emotional discharge

F. Persistent hypervigilance

G. Assumption things will improve with time
H.

XVII. ROLE OF PHYSICIAN * (SLIDE - ROLE OF PHYSICIAN)

A. Avoid stigmatizing, stereotyping
B. See child and family instead of disease
C. Realize uniqueness of every situation, adjust recommendations accordingly
D. Deal with own feelings of anxiety, frustration, helplessness
E. Be prepared to develop chronic relationship with child, family
F. Move from curing to caring model * (SLIDE - CARING)
    1. Clarification and control - examine problems forthrightly; provide accurate information
    2. Collaboration - share concern without becoming excessively distressed
    3. Directed relief - encourage expression of pent-up feelings
    4. Cooling off - modify tendencies to emotinal extremes
    5. Positive reframing and support
    6. Help family to identify coping resources