THE MANY FACES OF COPING:
A PERSONAL AND PROFESSIONAL JOURNEY

I. INTRODUCTION
    A. Psychologist in family medicine: taught for past 16 years
    B. Longstanding research and clinical interest in family coping
        1. family communication patterns - pediatric oncology
patients
        2. family functioning - Latino families w/ physically
disabled children
        3. support groups and meaning - developmentally disabled
    C. I would like to share with you a few of the things I have
learned in the process of my research and clinical work both about
the families I studied and about myself.

II. TECHNICAL DEFINITIONS OF COPING: SLIDE
    A. Coping refers to efforts to master conditions of harm,
threat, or challenge when routine or automatic responses are not
readily available
    B. Coping are efforts both action-oriented and intrapsychic, to
manage environmental and internal demands, and conflicts among
them, which tax or exceed a person's resources (Lazarus)
    C. Put even more broadly, coping is the response elicited by a
stressful event in order to minimize emotional and physical
distress

III. MODES OF COPING: SLIDE
    A. Problem-focused (instrumental)
        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
the problem
    B. Emotion-focused (palliative - affective regulation
        1. secondary coping
        2. when can't change outcome, change attitudes about outcome
        3. maintaining hope, emotional discharge, acceptance (+)
        4. Wishful thinking, avoidance of intrusive thoughts,
keeping feelings to oneself, distancing (-)
    C. Each of these may be both cognitive or behavioral
        1. Cognitive coping styles
            a. Minimization
            b. Vigilant focusing
        2. Behavioral
            a. Tackling
            b. Capitulating
    D. Coping may employ strategies of approach or avoidance

IV. ROLE OF APPRAISAL: SLIDE
    A. Coping is interactive with appraisal of the stressor
        1. What the event means to us

context in which disabled children and their families exist
    B. As one child said to me, "This handicap is not my problem. Your attitude about this handicap is my problem."
    C. Disability on a continuum of normalcy, but most people think of it dichotomously
    D. Spread effect
        1. Disability takes over child's identity
        2. Entire family is seen as having something wrong
    E. Stigmatization
        1. Disability seen as deviant, threatening
        2. Children, as well as adults, hold negative attitudes towards disability
    F. Intrapsychic organizing schemata to distance from disability
        1. I am intact and invulnerable
        2. There is a just world
        3. My world has meaning and coherence
        4. I am in control of my own life
        5. Disability challenges all these assumptions
    G. Discomfort of nondisabled in presence of disabled
        1. Reminds nondisabled of own vulnerability
        2. Underlying belief handicap represents punishment
        3. Fear of loss of mastery and control
    H. 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

VII. EFFECTIVE COPING: SLIDE

   A. For the past 15 years I have studied, interviewed, and spent
time with families whose children had leukemia and other cancers,
were physically disabled by polio and congenital birth defects, or
were mentally retarded as a result of Down Syndrome and other
genetic disorders.

   B. After awhile it became apparent that those families who were
coping most effectively, who appeared to have made a successful
adaptation, who had less stress, depression and anxiety, and better
physical health, shared some things in common:

   1. Personality resources
      a. Optimism
      b. Hardiness (commitment, control, challenge)
      c. Hope

   2. Acquiring and using social support: asking for help (all
kinds of help) and receiving it

   3. Communicating effectively: being able to share feelings and
fears, especially with those closest to them

   4. Developing instrumental skills of problem-solving and
information acquisition: knowing how to interact effectively with
a system, like a large hospital

   5. Being flexible in terms of what coping strategies they used
in responding to different aspects of a stressful event

   6. Using humor

   7. Capacity to grieve loss: to recognize the shattering of
certain dreams, and to create new dreams for themselves and their
families

   8. Ability to recognize and accept both normal and deviant
aspects of their child

   9. Identifying meaning: whether through religious conviction or
other experiences and beliefs, evolving a sense of purposiveness
and trust

VIII. NEGATIVE COPING: SLIDE
      A. Blame (self and others)
      B. Avoidance (chronic); escape; denial
      C. Obsessional wishful thinking
      D. Excessive self-controlling strategies/emotional discharge
      E. Persistent hypervigilance

IX. COPING WITH DISABILITY IN THE CONTEXT OF SOCIETY: SLIDE
      A. My research also taught me something about the social

more personal blame attribution (what we could call in lay terms, "blaming the victim")

5. My research also reflected a finding of larger studies: the isolation and lack of social support of disabled individuals and their families. Ironically, families who needed social support the most, often had least access to it

6. People who had not experienced disability tended to be glib about its effects. They stated confidently that having a disabled child would make them a better person. When they thought about how they might cope with such a situation, they tended to advocate a take charge, activist approach, supremely confident in their ability to successfully handle any crisis.

7. Parents who were actually coping with a disabled child were more sober about its effects, and they were more likely to value most highly being able to share their feelings, rather than effecting instrumental change.

PERSONAL LESSONS IN COPING

1. While busily engaged in these investigations, I was simultaneously aggressively pursuing tenure in the University of California system: trying to sustain a commuter-marriage with another high-powered professional; and completing my family of 3 children

2. When I first embarked on my research, I saw a large gap between my world and the world of these families: I was successful, normal, they were deviant, disabled. *spread effect*

3. But as time passed, and I touched their lives more intimately, it was the similarities between us which became most striking.

4. I began to understand that at a deep and previously unconscious level I had pursued this research to address fears and pains with which I was wrestling on a very personal ~~level~~ way

5. When I look back on that time of my professional life, I realize that very often I too felt disabled, handicapped:
   a. By being young (at that time) in a setting where the "old boys" held all the power
   b. By being a Ph.D. in a world of M.D.s
   c. By being a woman in a world of men

6. My primary modes of coping with my feelings of deviance, abnormality, and failure were strategies shown by the research literature to be ineffective: I vacillated between avoidance of my difficulties and self-blame

7. In many arenas, I came to realize that the system dealt with my "differences" by making me wrong:
   a. My very presence (in meetings, on committees) was often regarded as trivial, accidental, *anomalous* and perhaps threatening
   b. My research and teaching were frequently evaluated as being motivated by misguided and inappropriate (ie., insufficiently biomedical and reductionistic) premises

8. Like the families I was studying, I became isolated, cut off from possible sources of support and validation

SOME PERSONAL RESOLUTIONS

1. This was a time of considerable personal pain and anguish. The sense of not fitting, not belonging was especially strong as I approached the tenure decision, which in my case was accompanied by considerable controversy within my department, the formation of special ad hoc committees to review my application etc.

2. I realized that to survive, morally, spiritually, and emotionally, if not physically, I needed to learn to cope more successfully with my environment; and that the very people whom I had tried to compartmentalize as my "subjects" were also my teachers

3. It is from them, from those families, that I learned, however imperfectly, lessons of courage, perspective, compassion, grief, and love which came to provide an anchor of meaning in my life

4. As a woman who came of age during the feminist movement, I had always valued being self-reliant, competent, making things happen for myself — instrumental coping skills — and I saw that they worked

5. I still value these qualities, but I learned to value equally the ability to trust and let go, to ask for and accept help from others; to network w/ other women & to speak out about my experience

6. I learned not to allow the narrow world of my career, and the judgments of academia, to define me completely; and learned to put energy into and receive sustenance from family, friends, and my religious community

7. I learned the poignant message of living, in Carlos Casteneda's words, "With death as your advisor," to value and appreciate those things of true importance in life.

8. In the words of one child cancer patient, "I've learned to accept some suffering in my life, because ~~on the other side~~ along with of that suffering there is a lot of joy and laughter and hope."

9. I would like to think that the great ~~gift~~ teaching of my research to me has been to help me realize that disability is not something which afflicts only an unfortunate few, but is part of the human condition; but so also is the strength and courage to learn from and transcend our disabilities.