UC Irvine
UC Irvine Previously Published Works

Title
Assessment of family coping with illness.

Permalink
https://escholarship.org/uc/item/96x9b4fh

Journal
Psychosomatics, 27(4)

ISSN
0033-3182

Author
Shapiro, J

Publication Date
1986-04-01

Peer reviewed

eScholarship.org Powered by the California Digital Library
University of California

JOHANNA SHAPIRO, Ph.D.

Assessment of family coping with illness

ABSTRACT: Coping with the stress of a critical illness, a severe physical handicap, or a marked developmental delay is not only an individual response, but also represents a continuing interaction among family members and those closely associated with them, as well as with the outside environment. This article examines the characteristics of family coping, provides recommendations for facilitating improved coping, and presents criteria for assessing how well a family is responding to the problem.

Many definitions exist to facilitate understanding of the term coping. We speak of cognitive, affective, and behavioral coping strategies[1]; we refer to problem-focused, emotion-focused, palliative, and instrumental coping.[2] It is possible that the proliferation of terms is itself a coping strategy, a way of reassuring ourselves that abundant coping resources are available when things go wrong. Technical definitions of coping abound.[3-6] As scientists and researchers, we invent cognitive models and terms to label the phenomenon. But we are also healers and teachers, and need to remember the human context in which this "coping" occurs. When we go beyond the social science terminology, in fact "family coping" refers to how close relatives answer the questions: Why is my loved one suffering? And what can my response to that suffering be?[7]

Far from being abstract and theoretical, this definition is extremely relevant to ultimate goals of applied research, teaching, and clinical practice. When speaking about interventions to facilitate adaptive family coping, we can emphasize behavioral strategies, but ultimately we are helping families discover ways of being with each other and with the larger society that are meaningful and fulfilling.

Families whose children are stricken by life-threatening, disfiguring, or handicapping conditions often turn to the physician for help in managing on a daily basis and in satisfactorily integrating this experience into their lives.[8,9] Yet some physicians and other health care professionals may be ill prepared to address the overwhelming emotions and concerns of these parents. We do not have enough information as to why some families rise to the challenge of such a crisis, while others sink into a state of chronic stress.

Positive coping is the response we strive to elicit in patients and families. But what is it? What do we currently know about how patients and families cope? How do we distinguish adaptive from dysfunctional coping; what outcome criteria can we apply from a pragmatic and an ethical viewpoint? How do we apply a family systems approach to the study of coping?[10] What practical lessons for health care providers can be learned from such an analysis?

For the past several years, I have re-

Dr. Shapiro is associate professor in the department of family medicine at the University of California, Irvine Medical Center. Reprint requests to her there, 101 City Drive South, Orange, CA 92668.

searched and worked clinically with families of children who have cancer, physically handicapping conditions, or a variety of developmental delays. The intent was to discover the impact of these stressful events on the family, and to learn more about the process by which it responded to the event and the extent to which the stressor became integrated into family functioning. These families were forced to face questions of personal meaning that many of us, living in a society in which public physical suffering is no longer frequently evident, can often avoid: What meaning can there be in a world that encompasses the undeserved suffering of children?[11] How can we control, or respond to, the uncontrollable, chance "bad things," as Kushner writes,[12] that come into the lives of many or perhaps all of us?

In my observations, families that resolved these questions satisfactorily often achieved a certain harmony[13]; families that did not tended to decline into chaos and disintegration. Also, it became clear that coping is not simply an individual response, despite the fact that this is primarily how it has been studied; rather, it is an interactive process occurring between individuals who are significant to each other, usually within the family but also including friends, extended family, neighbors, and colleagues.[14,15]

In my own research, individual maternal psychological and physical adjustment correlated highly with overall family response to a handicapped child. Families that were highly disrupted by the presence of such a child, that had angry or prolonged negative feelings toward the child, or that perceived the child to be a burden tended to be also characterized by depressed and ill mothers.[16,17]

The concept of family coping remains insufficiently defined. Is it simply an aggregate of individual coping responses? Does it have to do with overall patterns of family function? We are beginning to accumulate evidence about family coping. What follows is an exploration of some important areas in the assessment of family coping, from both a research and a clinical perspective.

Areas in family coping

Value clarification in coping outcomes. The word "coping" is used in two contexts. We may refer to behavior elicited in response to a stressful event in order to minimize emotional distress as coping[5]: seeking information, changing physicians, sharing feelings with one's spouse—all these are coping responses. However, we also speak vernacularly of individuals and families as "coping," or "not coping," with a particular stressful event, which confers a certain positive value on coping per se. We must look carefully at the outcomes for assessing whether a family is coping well or poorly in this latter sense. What are the criteria by which we judge adaptive family coping? Some criteria have a certain face validity: for example, we might reach almost universal agreement that individuals who are less depressed and physically healthier are functioning better than those who are more depressed and having more illness episodes. Similarly, there might be widespread accord, when considering the family level, that families that are cohesive, able to express feelings, encourage independence in family members, and are not highly conflicted or extremely controlling[18,19] would be functioning better than families not characterized by these attributes. Findings from my own research demonstrate that some families, and some individuals, do function better in the face of a calamitous illness-related event than others.

Physicians or therapists uncomfortable dealing with their own feelings when confronted with a developmentally delayed child may unconsciously encourage families to avoid emotion-focused coping.

However, it is important to remember the extremely subjective nature of most outcome criteria, especially in a clinical context. For example, it has been pointed out[6] that in some cases survival might be a good measure of positive coping, whereas in other cases the quality of life becomes the more important criterion. This point is particularly significant in terms of physician training, when we may see residents applying their own idiosyncratic concepts of positive functioning to parents and families. For example, I recall one teaching situation in which a resident was enthusiastic about a family's coping ability because they seemed to have mastered all available information about Down's syndrome. A more thorough evaluation of this family revealed an almost total lack of communication between parents, a classic web of emotional silence[20] that had ensnared the entire family unit. From a clinical perspective, it is critical to elicit family goals and values[21]: what is important to them helps tailor the development of particular coping strategies to fit their specific situation.

Task-specific nature of coping. In Figure 1, an apparently unitary stressor, such as the diagnosis of leukemia, generates a multitude of adaptive tasks,[6] or areas in which parents need to act or respond in order to deal successfully with their child's illness. For example, the diagnosis of childhood cancer can generate the following

tasks: (1) learning what leukemia is—a knowledge task, (2) dealing with feelings of shock, disbelief, and fear—a personal task, (3) giving and getting support from spouse and family members—an interpersonal task, (4) identifying appropriate treatment modalities—an informational task, and (5) communicating the diagnosis to the community (school, neighbors)—a social-integrative task.[22] The list of potential adaptive tasks can vary greatly. In terms of assessment, we must first consider the stage theory of coping,[23-25] as represented in Figure 2, and learn to identify the adaptive tasks associated with different stages. We must then be able to assess different family members' ability to deal effectively with these tasks.

Some evidence[26] indicates that processes of family functioning equip families to deal with certain kinds of tasks better than others. For example, a family uneasy about the overt expression of emotion may be a family with excellent problem-solving skills but one unable to deal with the affective dimension of a life-threatening diagnosis. Similarly, the family member whose coping patterns violate family rules and myths[27] may be open to punishment and scapegoating by the rest of the family. During training, residents may project their own values and rules onto families with disastrous results. Physicians or therapists uncomfortable dealing with their own feelings when confronted with a developmentally delayed child may unconsciously encourage families to avoid emotion-focused coping, and support the family's engaging only in emotionally restricted kinds of coping strategies.

Flexibility in coping responses. This is really a corollary of the above point. The idea of "bad" *vs* "good" coping strategies may be somewhat simplistic,[3] and the "good" coping in fact is characterized by a flexible and broad range of available coping strategies, rather than by a specific kind of coping per se.[6,28] Thus, families that know how to problem solve and to express feelings[29] may do better (be less depressed, have fewer illness inci-

(continued)

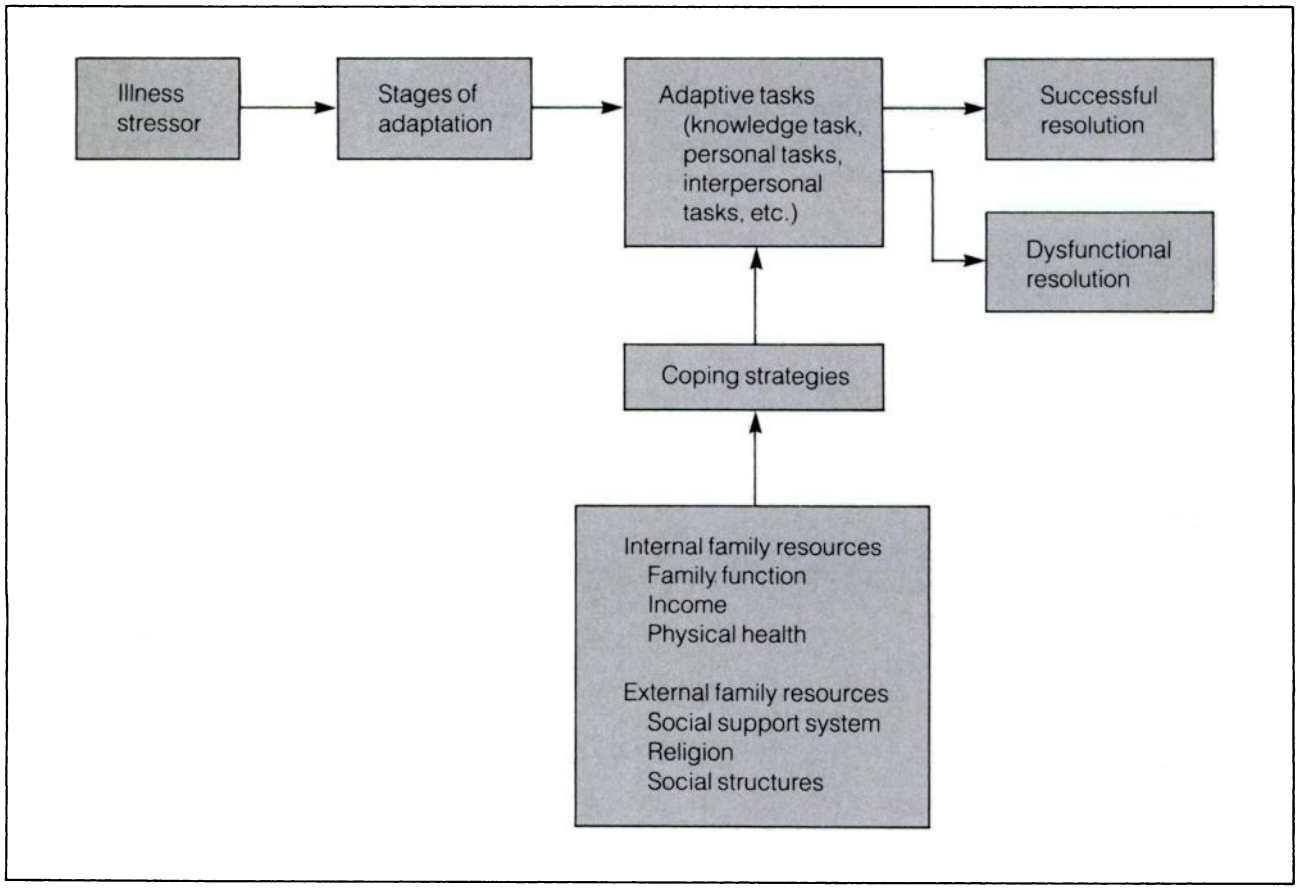

FIGURE 1—*Coping as a family: Family resources are drawn upon to facilitate adaptation following stress from a severe illness or crisis.*

dents) than families restricted to one modality or the other.

Positive vs *negative coping strategies*. That said, there is some evidence that certain coping strategies may be associated with positive outcomes, and some with negative outcomes. For example, in my own research, families with a handicapped child that communicated frequently, openly, and specifically about the child's problems were characterized by less depressed mothers, had fewer illness symptoms and episodes, and had more positive attitudes toward disabled persons than families where this kind of communication did not occur. Similarly, mothers who were able to seek emotional support from a variety of sources, who could use humor to deal with their child's problem, who felt in control of it, and who perceived themselves as having coping resources at their disposal were less depressed and in better health than mothers who did not use these strategies. Finally, mothers who used normalizing strategies (behavioral and cognitive coping strategies that increased the child's integration into the family and the community) also had higher levels of functioning. Mothers who favored avoidant and self-blame strategies tended to be more depressed, in poorer health, and had more negative attitudes toward the disabled.

Within-family coping. Some data[30-32] support the contention that by restructuring the family environment more positively, more adaptive outcomes for individual family members dealing with the stressor of illness may be generated. This evidence justifies the importance of working with the family as an entire unit, and focusing on improving certain general interactional processes within the family. For example, interventions that increase the family's overall ability to communicate and express feelings, that increase the amount of time the family spends in active recreational activities, and that reduce excessive chaos in daily family functioning will be associated with better physical and emotional functioning of the individual

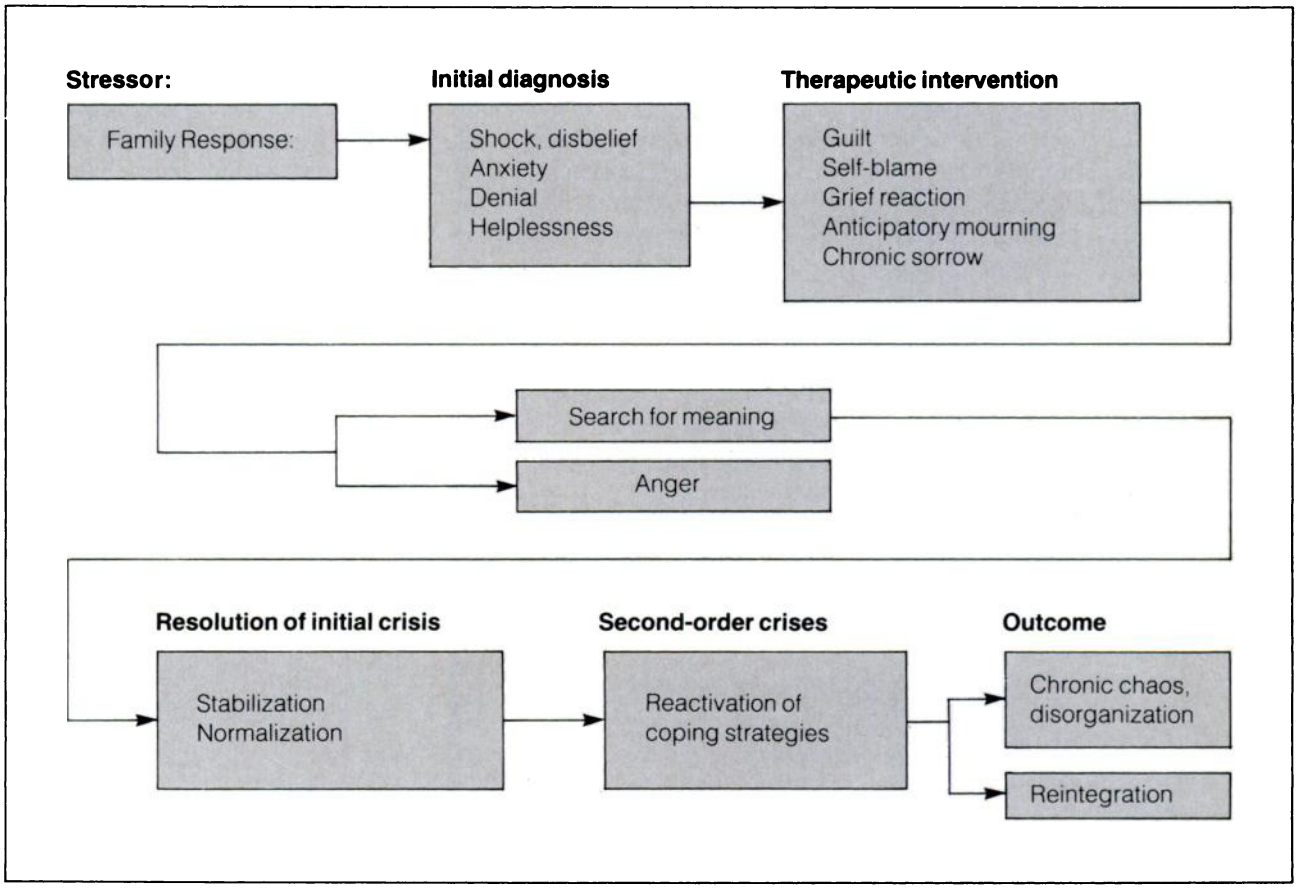

FIGURE 2—*Stage theory of family response to illness.*

family member.

In terms of specific family responses to a seriously ill or handicapped child, there is some indication that families in which other members besides the mother are involved in the child's care, and families that encourage normalization and integration of the child, are associated with more positive outcomes for individual family members [33-35]; conversely, families that cannot talk openly about the child and families with strong negative feelings about the child's condition are associated with more negative individual outcomes.

Finally, clinical evidence[18,36] suggests that families with serious discrepancies between family members in terms of stages of the adaptation process or in specific attitudes toward the child may be characterized by more negative individual outcomes. This concept of family discrepancy frequently translates into problems in terms of physician-family interactions. The less experienced physician may identify one particular family member as "right," and another as in need of enlightenment. Often the "right" family member corresponds to the physician's own stage of adaptive response to the child.

Family coping in relation to the larger society. One of the least addressed and most important influences on good family coping is the family's interface with the outside world. A major source of stress for families with a handicapped or chronically ill child is the nature of society's response.[37] In too many cases, this response is negative and punitive. In my own work, families with severely handicapped or ill children often used the analogy of crossing an invisible barrier into another world when their child was affected. "Until my child got cancer," or, "Until my child was born with a genetic defect," they will say, "I always thought that this kind of thing happened to other people." Further probing usually revealed that "other people" meant poor, uneducated, or incompetent persons, sinful people being punished by God, and basically persons very different from the respondent. Many individuals make attributions of parental blame when asked about a child suffering a life-threatening illness.[38] My work with poor Mexican families revealed a similar pattern in the case of handicapped children, suggesting that this is not a culture-specific phenomenon.

At the very time families may need social support the most, it may be least available to them.

Society, confronted with a handicapped or seriously ill child, must ask the question, Why? In an effort to allay fear, to impose some sort of order on a threatening world,[39] the answer frequently is blame. This happened because in some way the person affected was careless, bad, stupid, or irresponsible. The clear implication is that "it could never happen to me." Parents themselves may engage in self-blame, finding it easier to accept personal responsibility than to make a totally random attribution.

The phenomenon of societal blame has clear consequences for families. Families with ill and handicapped children have less social support than families of nonaffected children.[40] There also is clear evidence[41] that social support mediates stress in a positive way. We can have a situation in which at the very time families may need social support the most, it may be least available to them. Social isolation, ostracism, and stigma are not simply interesting sociologic concepts. They are pregnant friends who do not want to be around you because your baby was born "deformed." They are mothers who tell you that your autistic three-year-old should be castrated so that he will never reproduce. They are strangers in the market who whisper in audible tones that "children like that shouldn't be brought out in public." Such families are in great need of identifying support from the larger community where that is available, often in the form of support groups comprised of parents facing similar problems[42-44]; and of learning how to deal with society's fear and lack of understanding.

In regard to the caregiver, this is an important area for training. As a self-protective mechanism, all of us working with ill and afflicted families need some sense of separation, distance, and otherness. However, in the presence of these families, we can be caught up by our own sense of being threatened and vulnerable. When this happens, we must guard against subtly punishing these families, blaming them for being in this situation of suffering and pain.

In summary, in terms of assessing family coping, attention should be paid to the following: (1) Has this family been able to integrate the stressful experience of illness in a personally meaningful and coherent way? (2) Can we evaluate the family as doing fairly well in terms of individual members' physical and emotional adjustment, and in terms of overall family functioning? (3) Are there major discrepancies between family members in terms of stages of coping, of their interpretation of the child's condition, and of the coping strategies available to them and that are allowed by the family system? (4) Is there evidence of coping strategies associated with positive outcome, ie, open and concrete communication patterns

within the family, ability to seek out emotional support from a variety of sources, efforts directed at integration and normalization of the affected child, use of humor, problem-solving, and information acquisition? (5) Conversely, do we observe too much reliance on negative coping strategies, avoidance, and self-blame? (6) Do family members exhibit task-specific flexibility and variety in coping? (7) What is the family's position in relation to society? How is the family's support system functioning? (8) Most important, we must return in our teaching and in our practice to the Socratic injunction, know thyself. To be healers of families in distress, we must first be healed ourselves. Therapists who bring their own fears and defensiveness to family encounters may find themselves mirroring inappropriate attitudes by distancing from the very persons to be helped. □

REFERENCES

1. Cohen F, Lazarus RS: Active coping processes, coping dispositions, and recovery from surgery. *Psychosom Med* 35:375-389, 1973.
2. Lazarus RS: *Psychological Stress and the Coping Process*. New York, McGraw-Hill, 1966.
3. Antonovsky A: *Health, Stress, and Coping*. San Francisco, Jossey-Bass, 1979.
4. Weisman AD, Worden JW: The existential plight in cancer: Significance of the first 100 days. *Int J Psychiatry Med* 7:1-15, 1976-1977.
5. Pearlin LI, Schooler C: The structure of coping. *J Health Soc Behav* 19:2-21, 1978.
6. Cohen F, Lazarus RS: Coping with the stresses of illness, in Stone GC, Cohen F, Adler NE (eds): *Health Psychology*. San Francisco, Jossey-Bass, 1979, pp 217-254.
7. Wong PTP, Weiner B: When people ask 'why' questions, and the heuristics of attributional search. *J Pers Soc Psychol* 40:650-663, 1981.
8. Edelstein J, Strydom LM: The doctor's dilemma—How and when to tell the parents that their child is handicapped. *S Afr Med J* 59:534-536, 1981.
9. Grant WW: What parents of a chronically ill or dysfunctioning child always want to know but may be afraid to ask. *Clin Pediatr* 17:915-917, 1978.
10. Carmichael LP: The family in medicine, process or entity? *J Fam Pract* 3:562-563, 1976.
11. Taylor S: Adjustment to threatening events: A theory of cognitive adaptation. *Am Psychol* 1161-1173, 1983.
12. Kushner H: *When Bad Things Happen to Good People*. New York, Schocken Books, 1981.
13. Andolfi M: *Family Therapy: An Interactional Approach*. New York, Plenum Press, 1979.
14. McCubbin HI: Integrating coping behavior in family stress theory. *J Marr Fam* 41:237-244 1979.
15. McCubbin HI, Joy CB, Cauble AE, et al: Family stress and coping: A decade review. *J Marr Fam* 42:855-871, 1980.
16. Shapiro J, Tittle K: Individual and family correlates among poor, Spanish-speaking women of their attitudes and responses to children and adults with disabilities. *J Rehabil*, 1986, to be published.
17. Shapiro J, Tittle K: Poor Mexican mothers of disabled and nondisabled children: A comparison of maternal adjustment, child adjustment, social support, family function, and attitudes toward disabled persons. *Am J Orthopsychiatry*, 1986, to be published.
18. Moos RH: Evaluating family and work settings, in Ahmed P, Coelho G (eds): *Toward a New Definition of Health*. New York, Plenum, 1979, pp 337-360.
19. Moos RH, Moos B: A typology of family social environments. *Fam Proc* 15:357-372, 1976.
20. Turk J: Impact of cystic fibrosis on family functioning. *Pediatrics* 34:67-71, 1964.
21. Schank RC, Abelson RP: *Scripts, Plans, Goals, and Understanding: An Inquiry into Human Knowledge Structures*. Hillsdale, NJ, Erlbaum, 1977.
22. Adams DW: *Childhood Malignancy: The Psychosocial Care of the Child and His Family*. Springfield, Ill, Charles C Thomas, 1979.
23. Power PW, Del Orto AE: Impact of disability/illness on the child, in Power PW, Del Orto AE (eds): *Role of the Family in the Rehabilitation of the Physically Disabled*. Baltimore, University Park Press, 1980, pp 111-116.
24. Jacobson A: The child in the hospital, illness and death: A psychological process in four phases. *Sygeplejersken* 79:16-18, 1979.
25. Burr BB, Good JB, Del Vecchio-Good M: The impact of illness on the family, in Taylor RB (ed): *Family Medicine: Principles and Practice*. New York, Springer-Verlag, 1978, pp 221-233.
26. Bandler R, Grinder J, Satir V: *Changing with Families*. Palo Alto, Calif, Science and Behavior Books, 1976.
27. Goldenberg I, Goldenberg H: *Family Therapy: An Overview*. Monterey, Calif, Brooks/Cole Publishing, 1980.
28. Folkman S, Lazarus RS: An analysis of coping in a middle-aged community sample. *J Health Soc Behav* 21:219-239, 1980.
29. Lazarus RS, Cavnier R: Stress-related transactions between person and environment, in Pervin LA, Lewis M (eds): *Perspectives in Interactional Psychology*. New York, Plenum, 1978, pp 287-327.
30. Minuchin S, Baker L, Rosman BL, et al: A conceptual model of psychosomatic illness in children: Family organization and family therapy. *Arch Gen Psychiatry* 32:1031-1038, 1975.
31. Minuchin S, Fishman HC: *Family Therapy Techniques*. Cambridge, Mass, Harvard University Press, 1981.
32. Minuchin S, Rosman BL, Baker L: *Psychosomatic Families: Anorexia Nervosa in Context*. Cambridge, Mass, Harvard University Press, 1978.
33. Share L: Family communication in the crisis of a child's fatal illness: A literature review and analysis. *Omega* 3:187-201, 1972.
34. Minde KK: Coping styles of 34 adolescents with cerebral palsy. *Am J Psychiatry* 135:1344-1349, 1978.
33. Minde K, Hackett JD, Killou D, et al: How they grow up: Forty-one physically handicapped children and their families. *Am J Psychiatry* 128:1554-1560, 1972.
36. Smilkstein G: The family in trouble—How to tell. *J Fam Pract* 2:19-25, 1975.
37. Darling RB: *Families Against Society*. Beverly Hills, Calif, Sage Productions, 1979.
38. Shumaker SA, Shapiro J, Kellerman J: Parents' strategies for coping with cancer in their children: Sources and impact of self-blame. Presented at the Annual Meeting of the American Psychological Association, Los Angeles, August 1981.
39. Ryan R: *Blaming the Victim*. New York, Vintage Books, 1971.
40. Friedrich WN, Friedrich WL: Psychosocial assets of parents of handicapped and nonhandicapped children. *Am J Ment Defic* 85:551-553, 1981.
41. Haggerty RJ: Life stress, illness, and social supports. *Dev Med Child Neurol* 22:391-400, 1980.
42. Morgan M: Counselling parents who have a handicapped child. *J R Coll Physicians* 13:245-247, 1979.
43. Valman HB: The handicapped child. *Br Med J* 283:1166-1169, 1981.
44. Huberty DJ: Adapting to illness through family group. *Int J Psychiatry Med* 11:213-218, 1974.