

FAMILY REACTIONS AND COPING STRATEGIES IN RESPONSE TO THE PHYSICALLY ILL OR HANDICAPPED CHILD: A REVIEW

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Abstract—This article reviews a broad range of clinical and research material investigating the coping processes of individuals and families, particularly in response to a serious illness or handicapping condition in a child family member. The interactive effects of family and illness are established; then several theoretical, descriptive and empirical theories of coping are presented. Coping responses of family members and the family unit as a whole to minor illness, to chronic illness and handicapping conditions, to childhood cancer, and to death in childhood are all discussed. The article concludes with a discussion of the implications and benefits for the physician and other health care professionals in adopting a family-oriented treatment approach.

INTRODUCTION

This article will examine different forms of family reactions and coping strategies activated by a significant physical illness or handicapping condition in a child family member. The literature is replete with articles stressing the importance of family variables in considering issues of treatment, rehabilitation, and outcome. What is the rationale for this emphasis? This article briefly reviews evidence that there exists a powerful interactive effect between family and illness. It then explores the concepts of individual and family coping. Finally, it attempts to summarize what is known about family response to illness and handicapping conditions in children.

This review is necessarily restricted within certain limits: (1) Its focus is on the child as the identified patient. Available evidence suggests that while illness in one family member affects the entire family unit, which individual is ill also influences the nature of the family responses [1, 2]. By restricting the focus to the ill child and a responsive family, a fairly consistent frame of reference is created. It is also, at this point, the situation which has been shown to illustrate most clearly principles of family/illness interaction. (2) The review examines only two major interrelated issues: (a) the impact of the illness on the family and (b) the nature of coping strategies generated by the family in response to the illness. This emphasis was selected because it is at once of great potential clinical relevance and simultaneously extremely elusive in terms of concrete clinical implications.

A RELATIONSHIP BETWEEN FAMILY AND ILLNESS

It has been argued for many years that the family is an appropriate unit for health care intervention [3-10]; and it has been observed that a common physician error is overtreatment of the child and undertreatment of the family [11]. Simultaneously,

there has been interest generated in family ramifications of various chronic and life-threatening disease entities [12, 13] and several review articles exist in the literature [3, 14, 15].

It is by now clear that an undeniable relationship exists between family and illness, and that a specific illness both affects and is affected by the family context. Important implications for the nature of health care derive from this statement. If the response of the family to an illness has an ability to influence the outcome of that illness, or to influence secondary complications of the patient's illness (e.g. psychological sequelae), then we are justified in understanding and studying this response. Similarly, if the illness of one member produces effects on the family which reverberate in the health care system (e.g. development of physical symptomatology, affective disorders, alcoholism, etc.), then this also is worthy of attention. It is well-documented, for example, that uncontrolled events and events with long-term threat of loss and disappointment (such as physical illness) are more linked to psychiatric disorders (e.g. depression) than are controllable events (e.g. marriage) [16, 17].

In order to understand the nature of the interaction between family and illness, it is important to review briefly how the family functions as a system, for it is this property which allows for the interaction effects observed in the literature. The family system has been defined as a network of interpersonal relationships characterized by a continuous interchange between members and by reciprocal causal effects [18]. In this conceptualization, the family is viewed as an organic unit, a dynamic system in which every part is simultaneously organizing and being organized by other parts [19]. A systems approach to understanding the family [20] may be contrasted to a linear approach in that the latter identifies the individual as the patient and primary focus of treatment, and assumes that responses and behavior of the individual are determined by antecedent and consequent environmental forces [21]; while the former emphasizes feedback loops

for the first time in a well-documented, systematic fashion that the health of children and the outcome of disease were closely related to physical and psychological dimensions of family environment [62]. Other investigators have observed that children with chronic illness appear to do better in well-functioning than in poorer functioning families [7]. Other studies have documented that children coming from dysfunctional families were seen more frequently in physician offices for minor illness [63]. By contrast, in another study, 50 child nonattenders at a well-child clinic were compared to 50 regular attenders [64]. The former were characterized by multiple factors, including chronic, longstanding, multiple problems affecting the whole family.

Disorganization of the family also often leads to failure to provide basic adequate health care [15]. Parental deprivation has been associated with a number of psychosomatic and psychiatric diseases, notably suicide, tuberculosis and accidents. The relationship of marital status to overall mortality is especially striking with respect to tuberculosis, suicide, influenza, pneumonia, syphilis and cirrhosis. Family attitudes have also been shown to be significant in rheumatoid arthritis, mental illness, addiction and cardiovascular disease [65]. Further, the death of a spouse or the serious illness of one family member raises the statistical likelihood that other family members will also develop signs of illness [66].

On the other hand, there is little evidence that perceived family solidarity, marital happiness or close family ties 'protect' the family against the disruptive impact of a member's illness on family relations. In fact, in one study, just the opposite appeared to be true, and those with disparate family ties often reported being more drawn together by illness [67]. There was also little evidence to support the idea that egalitarian families were less likely to be adversely affected by a member's illness than were their more maternally dominated counterparts.

Of course, the interaction between family and illness is reciprocal, and illness can also change a family's dynamics. However, even this impact is mediated by the family's interpretation of the illness crisis. If the family interprets the illness as a threat, the crisis will produce anxiety; if it is interpreted as a loss, it will produce depression; and if it is interpreted as a challenge, both anxiety and hope will create problem-solving energy and promote motivation and growth within the family [68].

MODELS FOR UNDERSTANDING INDIVIDUAL AND FAMILY COPING

It is clear that some relationship exists between the family unit, the nature of family functioning, and various aspects of how an illness expresses itself. That being the case, it becomes particularly important to understand how the family copes with the child's ill health: how it reacts and what proactive strategies it employs to deal with this stressor.

Individual coping processes

Coping may be defined as all responses made by the individual who encounters a potentially harmful

outcome, including overt behaviors, cognitions, physiological responses and emotional reactions [69]. Lazarus [70] has defined coping as "efforts, both action-oriented and intrapsychic, to manage environmental and internal demands, and conflicts among them, which tax or exceed a person's resources". According to his formulation, coping efforts can be directed toward the threat itself, or toward efforts to regulate the emotional distress caused by the threat. The former style is instrumental or problem-solving, the latter labelled palliative [71].

It is important to make a distinction between coping resources and coping responses*. According to this formulation, a *coping response* is an action, thought, verbalization or feeling elicited by the stressor of illness [73], thus having a direct and identifiable link to this particular stressor. *Coping resources* [74], on the other hand, may be considered as aspects of the individual's external and/or internal environment which are either not directly or completely under the individual's control; they exist in a quiescent state, ready to mediate in a positive or negative direction the individual's response to the advent of a stressor. Clearly, the nature and type of coping responses generated by the individual will be determined to some extent by the coping resources available in that person's environment. While the exact nature of this relationship has not been specified, both theoretical and research efforts indicate that the presence of coping resources increases the range and effectiveness of the coping response [75, 76] while their absence would have the opposite effect.

Coping resources in the individual's internal environment might include stable, cross-situational personality attributes, such as self-concept [77] and psychological hardiness [78, 79]. They might also include the person's previous experience with other stressful situations [80]. In the external environment, such disease-specific factors as susceptibility, diagnosis and prognosis might also be categorized as coping resources (or deficits) [81]. Other coping resources might include demographic and socioeconomic variables (social class, marital status, educational attainment, financial status, religious affiliation) [82, 83]. Finally, both formal and informal support systems (group membership, friendship networks) [84, 85] also are resources available to the individual, although utilization of such systems by the individual would constitute a coping response.

Although it is generally agreed that coping responses act as a buffer between life stress and illness, judgments of positive versus negative coping are subjective and vague. Early work on coping tended to evaluate coping behavior as 'good' or 'bad' in and of themselves; i.e. individuals who engaged in emotional expression were coping well, while individuals characterized by intransigent denial were coping poorly [87]. Other researchers have identified different 'positive' coping responses, such as information-seeking, emotional control, maintaining a positive self-image and a sense of mastery [88]. Effective coping may also be inferred based on the relative maturity of the individual [89-91]. Finally, good coping may be defined with some circularity by the patients' own perceived success of their coping [92].

It may be said that positive coping alleviates the problem and reduces individual distress, while nega-

*For a more complete discussion of coping processes in serious illness, the reader is referred to Revenson [72].

tive coping exacerbates the problem and may become a problem in itself (e.g. drinking). Successful coping is often associated with specific outcome criteria in the anecdotal literature. For example, one author [93] judges that a family is coping successfully if (a) the family unit remains intact, (b) the family is able to accept the affected child, (c) there are normal sexual relations in the marital dyad, (d) siblings in the family have an age-appropriate awareness of the situation, (e) the family has retained their original primary care doctor, (f) the family has made concrete and realistic plans for the affected child, (g) safe passage through the different stages of coping has occurred, (h) parents express satisfaction with the management of their child, and (i) parents have a willingness to help in the management of other families facing a similar situation. Successful parental adaptation also has been said to be characterized by the enforcement of only necessary and realistic restrictions for the affected child; the promotion of peer interaction, self-care and school attendance; a tendency to isolate and deny anxious and helpless emotion, especially during a medical crisis.

Positive coping often depends on the support, through parent groups, of other families in similar situations [94, 95]. Good coping is also associated with such factors as good communication and assistance between parents; adequate financial resources and a willingness to use them in coping with the affected child; and functioning support systems [96]. Good adjustment to illness is found in families in which (a) there is a clear separation of the generations, (b) a satisfying of each other's emotional and psychological needs, (c) flexibility within roles, (d) toleration for individuation and (e) communication which is direct and consistent, and tends to confirm the self-esteem of the other [59].

Adaptive patient responses have been identified [97] as including realistic self-reliance; acceptance of physical limitations, but with the development of compensatory activities; the ability to express anxious, sad and angry feelings; guarded optimism during periods of clinical quiescence; denial and isolation of affect to cope with emotional distress; a focus on the here and now; and the effective use of support individuals. Positive coping in the affected child has also been associated with independence, contact with peers, achievement in school and participation in other normalization activities.

Several coping strategies have been clearly identified as maladaptive or dysfunctional in the literature, although these conclusions are based on anecdotal evidence more than on research findings [97, 98]. Prolonged poor adjustment in the identified patient is characterized by fearfulness, inactivity, dependency; or, in contrast, an overly independent attitude, engaging in prohibited, risk-taking behaviors; or finally, resentful hostile attitudes toward non-disabled or healthy individuals. Negative child coping has been labelled as centering around fear, withdrawal, regression, neurotic utilization of organic symptoms, clowning and low self-esteem.

On the family level, it has been noted that severe and unchanging denial of the reality of illness tends to impede successful adaptation. Isolation of the ill member while the rest of the family attempts to sur-

vive also is dysfunctional both for patient and family. Hypochondriasis in other family members may be an indication that the family is not coping well with the identified patient's illness. The continued projection of angry feelings onto other family members, with no efforts at resolution or movement, also is considered dysfunctional. Extreme regression on the part of siblings, and extreme rigidity on the part of the family system in the face of life-threatening illness are further danger signs of poor coping. Finally, a significant withdrawal from accustomed social interactions tends to be associated with dysfunctional coping. Other maladaptive coping strategies include flights into activity; unremitting hostility to health personnel; and feelings of being overwhelmed by the child's care.

However, despite such value judgments about positive and negative coping, other authors have emphasized that coping is an extremely person- and situation-specific phenomenon [17, 69]. Thus, it may not be useful to talk about successful coping independent of identifying the particular stressor(s) being confronted, and the particular internal and external resources of the person or family doing the confronting.

Illness may be viewed in several ways [69], all of which mediate the nature of the coping response elicited. It may be seen as a challenge, an enemy, a punishment, weakness, a relief, a strategy, an irreparable loss, a positive value (opportunity for growth and development). The adaptive tasks of illness, to which coping must address itself, include: (1) to reduce harmful environmental conditions and enhance prospects of recovery; (2) to tolerate or adjust to negative events and reality; (3) to maintain a positive self-image and to construct a new self concept, a new mode of self-being; (4) to maintain emotional equilibrium; and (5) to continue satisfying relationships with others.

Illness is most often perceived as a threat [99], and coping processes are activated to reduce, deflect or eliminate anticipated harm. Several coping styles may be employed. *Cognitive* coping styles may be divided into minimization, or a tendency to selective inattention, ignoring, denial, rationalizing of facts or significance of illness; or vigilant focusing; an obsessional hypervigilance, rigidity, and compulsivity about details of therapeutic management. *Affective* coping responses include fear, panic, anxiety, depression, anger, resentment, shame, disgust, helplessness. *Behavioral* coping strategies include tackling, characterized by active energetic engagement; capitulating, characterized by passivity, inactivity and helpless dependency; and avoidance, or the active effort to free oneself from the constraints implicitly in the acceptance of illness or injury. Other important concepts in considering the coping process are the roles of courage, will, and personal growth.

Several theories of coping have been proposed [100]. Klinger's incentive-disengagement theory states that the encounter of an obstacle or threatened loss increases the vigor of the initial response; but if unsuccessful, there will first be frustration and anger, then depression and subsequent disengagement from the goal. Wortman and Brehm have proposed an integrative coping model in which the nature of the individual's response to a potentially aversive out-

come depends on (1) the expectation of control over the outcome and (2) the outcome's importance. Seligman's learned helplessness model suggests that depression and a sense of victimization stem from the subject's interpretation that individual behavior will have no effect on outcome. Haan [89] distinguishes coping mechanisms, which are healthy, reality-oriented and conscious, from defense mechanisms, which are rigid, distorting and unconscious.

Lazarus [71] groups coping into problem-solving vs palliative responses, and identifies information-seeking, direct action, inhibition of action and intrapsychic modes. Lazarus has emphasized that a person's cognitive appraisal of a stressful situation will significantly influence the coping strategies elicited and the ultimate success of a person's adjustment. Potentially harmful situations may be conceptualized either as a threat or as a challenge (with the implied potential for mastery or gain). Lazarus suggests that the coping elicited in response to a stressor may be more important than the stressful event itself [17, 71]. Thus, coping may be considered both as changing the threatening event directly, and as changing one's appraisal of the threatening event or some combination of the two. It is both problem-solving and regulation of emotional distress.

Four models of coping have been generated based on the distinction between attribution of responsibility for a problem and attribution of responsibility for a solution [101]. In the *moral model*, the individual holds himself responsible for both problems and solutions; effective coping (resolution of problems) is based on proper motivation. The *compensatory model* argues that the individual is not responsible for the problem, but is responsible for the solution, and needs power to accomplish this. The *medical model* is based on the assumption that individuals are responsible neither for problems nor solution, and should be the passive recipients of treatment. In this case, 'coping' would consist of adaptive adjustment to the patient role. Finally, in the *enlightenment model*, individuals are seen as responsible for problems, but unwilling to provide solutions; in this view, they require discipline to move to the problem-solving level. The models are all based on a balance between blame (attribution of problems) and control (attribution of solutions).

Another model for understanding coping strategies is derived from Shapiro's work on control theory [102]. Basically, Shapiro posits a need for control as a fundamental human drive. A significant consequence of the illness experience is to render the individual helpless and out of control. The sick person becomes an object manipulated by forces beyond comprehension and regulation. Illness raises issues of vulnerability, and the fragility and transitoriness of life as well. Thus, an important coping task is to regain a sense of mastery and control at some level of existence. Many coping strategies seemed to be directed at the patient's (or parents') need to control the uncontrollable. This phenomenon has been posited as an alternative explanation to psychodynamic interpretations of guilt; i.e. parents prefer to blame themselves than to confront the helplessness of having nowhere specific to lay blame [103].

Thus, many coping strategies may be understood as an attempt to maintain a sense of control, whether

	Active	Passive
+	1 Active - Positive	2 Passive - Positive
-	3 Active - Negative	4 Passive - Negative

Fig. 1. A control model of coping.

over life in general, or over the outcomes of the illness in particular. In this regard, work on locus of control becomes relevant, as individuals may maintain a sense of control through a belief in personal efficacy (active participation in the recovery process); through a belief in chance; or through a belief in powerful others [104].

Shapiro posits a four quadrant model of control, which is divided into dimensions of active and passive control, as well as adaptive and dysfunctional control (see Fig. 1). In this model, quadrants 1 and 3 are active; 2 and 4 are passive; 1 and 2 are adaptive; 3 and 4 are dysfunctional. Using this model as a theoretical framework, we may examine further some of the commonly identified coping strategies. This conceptualization cuts across other coping models, in that adaptive strategies of active control may be either cognitive or behavioral, instrumental or palliative.

Adaptive, active control coping strategies would clearly include the following: information-seeking, direction action (or inhibition of action) regarding the illness: tackling strategies; mastery of specific illness-related procedures; and goal-setting, in the sense of mastery over the illness. It might also include making life changes in the hopes of positively affecting the outcome of the illness; and escaping or distracting behaviors to avoid, for a time, the reality of the illness.

One of the most commonly employed cognitive coping strategies is denial, or minimizing and avoiding. This can occur with reference to actual facts, to the meaning of those facts, or to one's own emotional state. Denial may also be interpreted as an active control coping strategy in the following sense. Active control coping strategies take as their basic premise that the disease is the enemy, and all efforts must be directed toward conquering or excising it. This is a typically Western mode of controlling the environment, through conquering and active mastery. In this sense, denial becomes a cognitive mechanism for rejecting the reality of the illness, or the limits it imposes. It is rooted in the effort to keep the individual intact by rejecting the intrusion of illness or its implications. Isolation of affect, or denial of the emotional effect of an illness crisis on the individual, may also be conceptualized in this manner. Similarly, mental imagery such as that used by the Simontons [105] with cancer patients is based on the idea of combatting and vanquishing cancer cells, and as such may be considered an adaptive active control strategy.

Coping strategies falling into quadrant 3 might include the following: obsessional hypervigilance, or the effort to be in active control of all aspects of the disease and its treatment; dysfunctional denial and avoidance; and control through thinking [106], in the sense of accumulating information and other forms of cognitive mastery in an attempt to obviate one's

essential helplessness in the face of an overwhelming stressor; intellectualization and denial of affect [107]. In this respect, more typically active outward-turning emotions such as anger might also be considered as falling in this quadrant 3, as they are based on a rejection of the illness.

Passive control coping strategies, on the other hand, appear to be organized around an acceptance of the disease, of essential helplessness, and of realistic limitations. Quadrant 2 adaptive passive coping strategies might be characterized by 'insight', or acceptance in the positive sense: continuing to live as fully as possible given the constraints of the illness. Other quadrant 2 strategies might include turning to others for support and encouragement; acceptance of and ability to express one's own feelings in this situation; and finding a general pattern or meaning in the experience. Rationalization, or focusing on the enriching aspects of the experience, might also be considered to fall within this quadrant. Rehearsing possible outcomes with the aim of gaining acceptance both of recovery and death also might be included in this category. Humor and laughter would also be considered adaptive passive coping strategies, in that they challenge not the outcome itself, but the interpretation of the seriousness of the outcome. Similarly, prayer in the sense of the accomplishment of God's will would be included in this quadrant, while praying specifically for the recovery of the patient would be a quadrant 1 coping behavior. Stress reduction behaviors, such as meditation, positive imagery, and relaxation would also fall in this quadrant if their object was the increased centeredness and tranquility of the participant. Dysfunctional quadrant 4 strategies would include capitulating, focus on helplessness, hopelessness, and pervasive dependency; feelings of depression and low self-esteem (self-blame); and negative acceptance in the sense of resignation and giving-up.

Coping in children

Very little has been written specifically on child patterns of coping with stress. Rutter [16] examines mediating mechanisms of stress in children and points out that first, stress has a cumulative effect; and second, that (1) favorable home environment, (2) self-esteem, (3) availability of environmental options, (4) structure and control in the family and (5) stable relationships with adults were protective factors associated with better social adjustment in children. Rutter identified positive self-esteem, ability to derive pleasure in life, adaptability and malleability as coping skills which protected against psychiatric disorder in childhood under conditions of chronic stress.

Family coping

Family health has been defined as its capacity to effectively cope with illness events. An effectively coping family is able to attain a new adaptive equilibrium around a particular illness. Thus, the healthy family is not one that does not experience illness, but one that is able to cope with the demands of illness [6]. Little has been examined in the way of family coping *per se*. The most extensive work done in this area [108-110]

has identified several family coping responses to stressful separations, including seeking resolutions and expressing feelings; reducing anxiety; maintaining family integrity; religion and faith; establishing independence and self-sufficiency; building and utilizing interpersonal relationships. At this point, however, it is unclear in what sense it is possible to talk about family coping as more than an aggregate of the coping strategies of individual family members.

The goals of family coping strategies in response to major illness may be summarized as follows: (1) Responding to the challenge of family adaptation. Does the family have a sufficiently large capacity for transformation to include this development and encompass it? (2) Maintaining a sense of membership in the family for the ill person. (3) Reorganizing the family and reassigning roles. (4) Reestablishing an emotional baseline—and the mastery of resentful, self-accusatory and other negative feelings [111]. Another family coping goal has been conceptualized as maintaining relationships with the child which afford some parental gratification and at the same time fulfill the child's physical and psychological needs. Other family tasks when confronted with a chronically ill child include an effort to contain the impact of the child's illness and to develop expertise about their child's condition [112]. The family's overall coping style is influenced by (a) the characteristics of the event, (b) the perceived threat to family relationships, status and goals, (c) the resources available to the family and (d) past experience with crisis situations.

Stage models of family coping

The most prevalent approach to understanding and conceptualizing family response to physical illness in the child has been through use of the stage model [93, 113-116]. Most of these models are derived from observations of family response to the chronically ill, the physically handicapped or patients suffering from cancer. In their progression, they are generally quite similar to Kubler-Ross' classic stages of death and dying [117]—grief, denial, anger, bargaining, depression and acceptance. In general, they are not explanatory models, in the sense that they offer no insights as to why particular processes occur. They attempt to define a normal course of development for the psychosocial aspects of the family's reaction to the patient's disease. Their stated goal is to allow the physician to predict, anticipate, and deal with the family's response to illness, and to help discriminate between normal and pathological responses. Although there is considerable variability among models, all have certain elements in common. Acute coping reactions tend to reflect denial, overprotection, anger, guilt and blame; while chronic coping reactions have been categorized as masochistic, overprotective, withdrawal, doctor-shopping, denial and hope [97]. Stage theory has been collapsed temporarily and applied to situations of short duration, such as the child in the ICU [118]. However, these stages also closely parallel those identified in coping over time: (1) shock, disbelief, helplessness; (2) search for etiology and self-blame; (3) once the child is stable, anticipatory waiting, concern for the future; and (4) elation or mourning, depending on the outcome.

In most of these models, there is universal agreement that the initial response of family members to the child's diagnosis consists of shock, disbelief, anxiety, denial and helplessness. This is then followed by guilt, self-blame, depression and a generalized grief reaction [94], often including anticipatory mourning and/or chronic sorrow. There may also be an interval of searching for meaning, questioning reasons and values [119]. This stage may be followed by anger. Often, a stabilization is achieved after resolution of the initial crisis, only to be destroyed by second-order crises (relapse, entering school) [120]. Finally, the family comes to a point of chronic deterioration and disorganization, or reintegration. Adams, in an exhaustive work on childhood malignancy and its psychosocial ramifications [121], interprets family response in terms of anticipatory mourning and anticipatory grieving. He identifies the employment by the family of: (1) defense mechanisms: denial, repression, isolation of affect and avoidance; (2) affective responses: sorrow, anger, guilt, anxiety; and (3) adaptational responses: information-seeking, invoking emotional support, partialization or compartmentalization (focus on the moment) and rehearsing death. This is similar, although more detailed, to other family models of coping with cancer [113, 122].

One important and comprehensive stage model for understanding family response to illness is that of the family-illness trajectory [123]: Stage I raises legitimacy issues, and examines the nature of response to the onset of illness. Stage II deals with the reaction to diagnosis, including common phenomena of shock, anxiety, denial, disbelief and anticipatory grief. Stage III, the therapeutic intervention, emphasizes the importance of creating consistency between the family's belief system and the mode of therapeutic intervention; dealing with guilt/anger over helplessness; and dealing with assumption of responsibility for health care. Stage IV deals with early adjustment to outcome (recovery) and emphasizes issues such as regression in the child; delayed reactions of depression in the family; the reassignment of familial roles; the heightened sense of vulnerability; and what kind of relabeling occurs in the family. Stage V is the adjustment to the permanency of outcome and acceptance of death or permanent disability.

Despite its neat conceptual appeal, the stage model suffers from several deficits. For example, at present there is little research evidence to suggest the validity of this developmental approach, and it may be an example of shared, consensual thinking rather than reality. Secondly, it severely restricts the amount of options available to individuals in terms of coping. Because of the theoretical nature of the terms employed, it is difficult to know on a more concrete, behavioral level how the various stages are manifest. In all these models, it is unclear as to whether these stages are necessarily sequential. Perhaps stages may be omitted entirely, or conversely repeated or reverted to. Finally, and most complex, different family members may experience different stages at different times.

Family coping in psychosomatogenic families

One model for family coping with disease in the child which deserves special mention is Minuchin's

psychosomatogenic family [124-126]. Psychosomatogenic (or psychosomatic) families are fascinating examples of the potentially endless interactive effects of family and illness. In these situations, the family is not only responding to a particular type of illness (e.g. some cases of childhood asthma, brittle juvenile diabetes and anorexia nervosa); but in fact their method of 'coping' with the disease exacerbates and perhaps precipitates illness episodes.

Minuchin identifies the psychosomatic family as characterized by four components [127-129]: (1) enmeshment, or an overinvolvement of family members with a lack of boundaries between familial subsystems (groupings of certain family members—siblings, grandmother/granddaughter, all males—within the family); (2) overprotectiveness, especially where physical signs and symptoms are concerned; (3) rigidity, or a lack of ability to accommodate change and growth within the family system; and (4) inability to deal overtly with conflict, leading to the sublimation of conflict through symptoms of the identified patient. In one study [130], psychosomatic families were significantly worse than controls in that they failed totally to cope with experimentally induced conflict, and had vague and unclear communication patterns characterized by avoidance of conflict and pseudo-agreement. In families of patients with duodenal ulcers, the mothers exerted obsessional control and banned direct expression of aggression, while fathers were mild-mannered and distant [131]. In psychosomatic families, concern and preoccupation with the patient is used to avoid family conflicts [132, 133], but has the result of reinforcing symptomatology. Thus, illness in the child [134] may stabilize the family unit, resulting in a pattern of chronic illness. If the symptoms are alleviated, other family members may exhibit psychosomatic outbreak or other dysfunction. In these families, a clear relationship between emotional conflict and onset of symptoms tends to emerge [135]. The patient is externalizing by his/her symptoms the pathology inherent in the family system and therapeutic treatment modalities are generally undermined unless change also occurs in the family system.

Issues in family coping

Most models of coping have focused primarily on the individual. Even the stage models enumerated above do not specify precisely how the family experiences these different stages. Family coping is a new concept in need of further theoretical formulation. For example, does family coping mean simply the aggregate of individual family members' styles of coping? Does it refer to the discrepancies of stage coping between family members? Can the family unit function as a whole in such a way as to produce 'family coping' at a structural and/or process level? There are insufficient literature and research to adequately answer these questions. However, some speculation on these topics is appropriate, if only as a stimulation to further investigation.

Family members' coping response can be categorized in a variety of ways. An important dimension to consider is intentionality: i.e. whether the individual family member (or the family group as a whole) is consciously selecting a strategy as a means of dealing

with the stressor; or whether the individuals of the family group simply respond, and those behaviors, thoughts, and emotions are labelled by an outside observer as 'coping' with the stressor. This is an important dimension because future investigation may show that intentional strategies are more effective in terms of various outcome measures than unintentional strategies.

The most obvious intentional strategies are related to problem-solving. These may involve information-seeking, decisions to take (or not take) action, participation in treatment process, etc. Intentional cognitive strategies may also be categorized under this heading: for example, if a conscious effort is made to think positively, or to make encouraging self-statements. Less frequently, but theoretically possible, we see as examples of intentionality positive acceptance, where an individual or family group consciously selects a particular acceptance strategy to practice (meditation exercises, relaxation techniques).

Clearly, the 'problem' confronting the family is not unidimensional; thus, it may be appropriate to identify the various adaptive tasks generated by a single illness stressor. As various aspects of the illness are delineated, different coping mechanisms may be called into play. For example, one task to be addressed in the child cancer patient is that he/she receive the best possible and most appropriate medical treatment. Therefore, parents may devise strategies to allow them an active influence on this aspect of the stressor. However, another task to arise might be the child's quality of life. To deal with this issue, parents might problem-solve by spending more time with the affected child, engaging in more pleasurable activities together.

Thus, there are several different aspects of the stressor of illness. One has to do with the physical health of the affected child, and how that can be optimized. A second has to do with the emotional health of the affected child, and how that can be optimized. A third has to do with managing the emotional (and to a less extent, the physical) impact on parents of the child's illness. The fourth involves managing the emotional and physical impact on siblings.

Clearly, these areas are highly interrelated, and the coping strategy selected may alternatively (a) be helpful in one area and irrelevant to other areas of concern, (b) be helpful simultaneously in two or more areas, (c) be harmful simultaneously in two or more areas and (d) be helpful in one area and harmful in another area. An example of (c) would be a parent's denial of a diagnosis of ALL, which would negatively affect the physical health of the affected child, and in an extreme form also negatively affect the parent's own emotional health. An example of (b) would be increasing the number of mutually perceived enjoyable activities that parent and child engaged in, which would have a positive impact on the psychological health of both parent and child. An example of (d) would be a parent who, to deal with her own level of stress, would physically leave her child at a point close to the child's death. While such an action might be necessary to reduce parental stress, it would have a deleterious emotional effect on the child.

Much of the thinking on coping becomes quickly circular. For example, is 'feeling guilty' a coping re-

sponse to diagnosis? From a psychoanalytic point of view, the answer would be yes. This raises the possibility that coping strategies in themselves, which families employ either consciously or nonconsciously, may engender further coping strategies, required to deal with the consequences of the initial coping strategies. In this case, attending a support group might be a positive way to deal with guilt feelings.

There is also considerable confusion about how to evaluate coping strategies: i.e. what outcome measures are appropriate? Quick judgments in this area are clearly risky, for example, pejoratively labeling a parental response as denial, a word with definite negative connotations. Perhaps definitions of functionality are most useful. For example, any strategy which decreases the emotional or physical wellbeing of its user might be considered negative. Of course, these things are not easy to measure. But clearly excessive use of drugs or alcohol; eating disorders; significant and prolonged depression; phobic response are all negative in the sense that they negatively affect the health of the individual engaging in them. The individual's subjective perception is also of importance. For example, an individual who says, "I feel better when I try to look on the bright side", may be employing a strategy which is personally useful.

Another important idea is the concept of relating different coping strategies to different stages of a disease. It may be more 'appropriate' to feel shock and disbelief on the day of diagnosis than on the day of the child's death. Similarly, active problem-solving strategies may be better suited to the early phases of a disease, while nonjudgmental, acceptance strategies may be more appropriate during a terminal phase.

Several as yet unanswered questions emerge from the coping literature as a whole. For example, what are the factors which reduce a person's subjective distress when an aversive event is encountered? What are the conditions under which exposure to unpleasant events results in undesirable outcomes? Perhaps flexibility, and the range of coping behaviors is the most critical determinant. Perhaps the avoidance of obviously negative strategies is more important than which good strategies have been selected. When does exposure to negative outcomes produce renewed determination to overcome obstacles, and when does it result in feelings of helplessness and passivity? Of particular interest is the question of individual differences in responses to stressful events. For example, why, when confronted by equally stressful situations, do certain individuals appear to cope better than others? What is the phenomenon of resiliency and how can it be applied to the concept of family coping? Are there universal reactions to aversive life events (e.g. shock, anger, depression)? Is there an orderly progression through a sequence of stages of coping through which everyone proceeds? Finally, and most complex, what really is successful adjustment to an aversive life event?

FAMILY COPING WITH MINOR ILLNESS

As one might expect, little has been written about the response of the family to minor illness. It is often assumed that because minor illness is, after all, minor,

any impact or challenges it presents also will be minor. However, there is evidence to suggest that the child's negative response to minor illness is related to later hypochondriasis, persistent dependence, and excessive fear of physical hurt. Thus, a family's and patient's responses to minor illness are significant if only because of the potential chronic anxiety engendered [136].

Responses to minor illness of the child-patient have been noted most frequently [68, 137, 138]. The affected child often experiences reactions of guilt, fear, anger, depression, apathy, loss of normal social contacts, restrictions and a changed relationship with parents (either in the form of increased indulgence or hostility). This response in some ways parallels the commonly reported reactions of the child to major illness and even to death and dying. Behavioral changes, particularly in the age range 1-4 years, have also been documented, including clinging, fear of being alone, fear of going to bed, feeding problems, enuresis, general anxieties, nightmares, jealousy of other children, being more babyish and loving the mother more. Younger children tend to become regressive and dependent, while 3-4 year olds tend to be irritable and to withdraw.

Parents are also affected by the minor illnesses of their child and it is interesting to note that mother's reaction to the illness is the most important etiological factor in any subsequent behavioral disturbances in the child. Parents respond with fears, guilt, anxiety, fatigue, depression and may have misconceptions about the illness. Marital discord often increases. Depending on the nature of the experience itself, parents emerge from the illness either frightened and confused or with a feeling of mastery and accomplishment [136]. It has also been noted that siblings may exhibit behavioral problems during the minor illness of another child in the family.

Virtually nothing has been written about how parents and child cope with the stress of minor illness. It has been observed, in terms of dysfunctional coping, that physicians may be pressured to either overmanage or undermanage minor illness because of intrafamilial dynamics.

FAMILY COPING WITH CHRONIC ILLNESS

The family is affected in profound ways by the occurrence of a chronic and/or life-threatening illness. The family has the responsibility for mediating stress for its members [139]. However, great or prolonged stress can destroy the role of the family as buffer for its members. Both individual and family reactions to such threats as prolonged illness are formed from one to four weeks after the diagnosis is confirmed; both maladaptive and adaptive coping responses become evident then, and these responses persist and are reinforced throughout the course of the illness. The depth of the family response may be seen in the vulnerable child syndrome, or children mistakenly identified to be at risk for or suffering from some serious physical condition. In one study [140] it was found that years afterwards, the misdiagnosed child was still perceived differently and treated differently by the mother. (For an opposite finding see [141].) The most important

variable in this situation was the maternal reaction to the baby's illness, rather than the physician's opinion or the objective severity of the disease.

We are beginning to be able to generalize about the responses of families to serious illness in the child. Dysfunctional responses seem to have received the greatest attention in the literature. This list is a lengthy one [142-145]. Initial responses of shock, denial, guilt, inadequacy and helplessness are commonly reported [94]. Resolution of these feelings is apparently quite variable. Resentment, irritation at the unexpected burden and anger are also possible reactions [146], yielding either punishment, rejection or ignoring of the ill member. Mothers may develop unrealistically low expectations for their child to protect themselves from disappointment and adopt a custodial rather than a parental role [96]. Even more common are feelings of anxiety and uncertainty, often producing overprotectiveness and overindulgence toward the patient. Anxiety may focus initially on the appearance and/or care of the child, and later may be directed to questions of future function and/or survival. Depression and unresolved grief or anticipatory mourning are also frequently reported consequences. There exists some research evidence to support the belief that higher levels of depression and anxiety exist in mothers of handicapped children than in the general population [147]. The frequently reported phenomenon of 'chronic sorrow' [119] refers to parental emotional response to their child's handicap or chronic illness, where, because the child does not die, parents must deal with issues of loss and disappointment on an ongoing, often unresolved basis.

Further, parents' sense of competence appears to be severely challenged by the presence of a chronic health condition in their child, especially for fathers. Fathers also seem to derive less satisfaction and gratification from these children than do fathers of normal controls [148]. At times, parents become so preoccupied with their own feelings that they are unable to contribute adequate emotional support to the child. Marital dysfunction is frequently mentioned, and it has been pointed out that the stress of dealing with a chronically ill or handicapped child can destroy family life [115]. However, it is not clear that a significantly higher divorce rate is characteristic of families coping with a major illness [149-153].

Parents of affected children often display both psychosomatic and psychiatric illnesses, especially depressive disorders [154]. Parents may also experience sleep disturbances, nightmares, increase in smoking, anorexia and a need for tranquilizers and sedation [155]. They may report themselves to be tired, worried and generally unwell [156].

Frequently, overconcentration of attention on the sick member is reported, and child-rearing practices are distorted, influenced by parental guilt, ambivalence, depression or rejection [157]. Often, mother becomes overinvolved in an intense dyadic relationship with the identified patient, while father, and to some extent other siblings [158-160] are isolated outside the 'magic circle'. Even more generally, there is an overall distortion of family life, as the ill child becomes the center of attention, and the hub of the family for whom considerable lifestyle and financial sacrifices are made [161].

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Very often, a chronic stress syndrome is identified in the family, where the main goal of the family becomes physical survival, with little hope of accomplishing or identifying goals. Often, in long-term adaptation, the family fluctuates between feelings of mourning and denial. Sometimes, lethal dyads emerge [145] characterized by a see-saw of symptoms between family members. Families with a chronically ill or dying member are frequently characterized by a web of silence [162], a notable lack of communication in the household about the disease, and the consequent isolation of the patient. Communication within the family also can be a major problem because family members may be at different stages of the grief process [119], and are threatened by the perceptions of other family members. In response to chronic and/or fatal illness, parental communication often ceases altogether as a result of psychological processes of guilt, blame, denial and depression [163]. Parents also seem to lose touch affectively with their children, and to be unaware of the child's fears and fantasies concerning the illness.

Another kind of isolation occurs for the family itself. Families struggling with chronic disabling or life-threatening conditions may become isolated from the large society, and often view themselves in a we-they relationship with the outside world [164]. Because of this feeling, a family may at times postpone or avoid seeking help. Finally, there are significant infringements on family's leisure and work time, as well as on time with spouse and time for self [165].

Initially, during the first episodes of serious illness, family members still maintain a spirit of hopefulness and helpfulness. In relapse, a process of disintegration sets in, and splits appear within the family group. Family members begin to drift apart. In the 'pseudo-narcotic' syndrome [166], family members walk about in a dazed state: there is a sense of profound apathy, a loss of feeling, impoverished interaction between family members, diminution of sexual desire and loss of contact with the outside world. Where there is past evidence of family strength, this disintegrative process may be halted and reversed. Attempts are made at denial of deviance, and rationalization of symptoms. Then an effort is made to localize the disturbance by isolating the patient. This may be followed by a turning to outside connections and social affiliations. Eventually the patient's perspective is understood, and viewed with compassion. Often, this regeneration is characterized by outbursts of creativity in family members.

Coping responses specific to the affected child have also been noted. It has been observed [167] that in terms of the psychological effect on the child, the illness itself is less menacing than familial response to that illness. About 10% of all children will be affected by chronic illness by age 15, and one third of these will develop secondary psychological complications [168]. These secondary psychological and behavioral pathologies are an attempt to cope with the stress of meeting the demands of daily living. Maladaptive responses in the pre-adolescent include demoralization, self-denigration, denial and depression. Interestingly, in a study of 100 7-12 year old children hospitalized for orthopedic procedures, of the 23 diagnosed as clinically depressed, significantly more had parents

with adjustment or emotional problems (problems in adjusting to the child's handicap; extreme anxiety about present and future; intense guilt feelings; fault-finding and teasing child; intense marital discord; extreme overprotectiveness; and a subjective perception of the handicap as more stressful than parents of non-depressed children perceived their child's handicap).

Of course, there is at times the effect of secondary gain for the child, in the sense of increased attention, special treatment and privileges, etc. However, this does not compensate for the negative feelings of low self-esteem, moodiness, withdrawal, depression, oversensitivity, denial, rebellion, overdependence, immaturity and passive resignation which often affect the chronically ill child. Like his or her parents, the child also experiences anxiety, shame, deviance, a sense of doom and failure, a sense of 'badness', fears of death, denial, guilt and anger [169]. The child may either internalize his/her predicament as a punishment, or project blame onto the parents for causing him/her to be defective. The child may also become isolated from peers. Behavioral problems are often an issue [157, 170]. The combined presence of chronic illness and a low level of family functioning serves to increase the probability that a child will be described as having three or more deviant behavioral symptoms.

Just as family relationships and communication patterns are critical in determining the affected child's response to serious illness, so these are often more important in determining siblings' reactions than the type and severity of the illness itself [171]. Siblings particularly at risk for maladaptive responses are undergoing other, concurrent stresses, have poor relationships with parents and/or with the ill child, poor support systems, and limited communication skills. They may themselves develop physical symptoms, school problems, anti-social or attention-seeking behaviors, changes in mood, regressive behaviors, or anxiety-related habits (nightmares, fears, accident-proneness, nailbiting, stuttering, eating problems) and poor self-esteem. Sibling effects also reported prevalent include feelings of being deprived of emotional or material support; behavior problems [94]; excessive involvement with the sick child; and some degree of social isolation and alienation. Other studies report that siblings fear they themselves may become ill or have caused the patient's condition [118]. Other sibling problems in cases of chronic illness include jealousy, enuresis, encopresis and fire-setting [172]. Often the sibling suffers even more psychological distress than the affected child [173].

However, there appear to be some positive responses as well in the family confronted with major and life-threatening illness. These appear to be reported more commonly in the popular literature, or in anecdotal form. Several anecdotal reports stress the feelings of happiness and growth that come from sharing this experience with their child [174]. Indeed, some researchers have dismissed these positive consequences as rationalizations on the part of parents attempting to keep their defenses intact. On the other hand, parents sometimes report that professionals put too much emphasis on the negative aspects of the experience, and underestimate their capacity to make adjustments after the initial shock has dissipated. It

seems valid to consider these responses for what we can learn about making life-threatening illness a major growth experience for the family.

Families often report becoming closer as a unit, developing a true sense of family for perhaps the first time [175]. Family members also sometimes feel they have grown on a variety of personal and interpersonal dimensions as a result of the experience [176]. Specifically, the development of a more positive and humorous worldview is sometimes reported, as is an increased compassion and tolerance [177]. Also reported is the development of unusually deep and meaningful friendships, both with other parents and at times with hospital personnel. These families often report a basic normalcy and independence, as well as an unusual maturity, in their affected child [178]. One research study of adolescent illness in relation to parental relationships found that when chronically ill adolescents were overtly ill, there were noticeably positive changes in the reactions of family members [179]. Perhaps reality lies somewhere between these findings. One study indicated that in terms of coping, parents raising a physically handicapped child fell between normal and poorly-adjusted parents [180]. There was lower parental confidence, understanding and less acceptance of the child than in a normal population, but greater than in poorly functioning families. Similarly, the children themselves had more behavior problems than normal children, but less than emotionally disturbed children.

COPING IN FAMILIES WITH A HANDICAPPED CHILD

Both anecdotal observation and survey methodology have been used to report on the effect of a handicapping condition on the family and on the family's coping response to such a condition. Existing summaries [157, 181, 182], based primarily on opinion and case studies, stress the high morbidity of parents and/or children due to (1) lack of acceptance of such a child and (2) severity of stress imposed on the family. Several studies [119, 183, 184] refer to identifiable phases which families undergo as a result of their child's disability, similar to the stages identified in the death and dying literature. For parents of a handicapped child, these include initial shock and disbelief, often followed by rage, guilt, denial and adjustment or acceptance. Reference is also made to the phenomenon of chronic sorrow [115]. Another important theoretical concept is that of marginality, in which both parents and child must come to terms simultaneously with the child's normal and deviant aspects [185].

Several articles attempt to distinguish between successful and unsuccessful coping in parents and family of the disabled child. Denhoff [186] concludes that good coping on the part of parents consists of (1) acceptance, (2) developmental understanding, (3) warm and secure family relationships, (4) encouragement of self-help, (5) initiative and stamina in the area of therapy and rehabilitation and (6) professional trust. Another article, examining the adaptive patterns of parents of amputee children [187], mentions as indices of good coping the importance of love and acceptance, communication within the family, limit

setting for the affected child, and flexibility in managing daily crises. An English study [188] gathered survey material on the problems of 50 handicapped children and their families. This study identified widespread emotional difficulties in the parents, such as over-anxiety, depression, over-protection, rejection, friction and aggression. Among siblings, poor coping was marked by jealousy, a negative effect on their social life, and a negative effect on family leisure time. For the affected child, poor coping was associated with withdrawal, behavior problems, anxiety, depression, temper tantrums, enuresis and aggression.

A study of 25 children and families [164] emphasized the importance of realistic acceptance of the child's condition and prognosis, and the importance of effective information-seeking and help-seeking. According to parents surveyed in this study, successful coping meant achieving a quality of life as close to normalcy as possible. This study, as do others [95, 189], also emphasized communication efforts and utilization of support systems as positive coping strategies. The study previously cited which concluded that coping styles of parents raising a handicapped child fell somewhere between normal and poorly-adjusted parents [180], emphasized that the presence of the ill child was the primary contributor to these patterns. Several articles [94, 171, 190-194] specifically discuss the use of family groups as part of a coping stratagem. Most of these groups were led either by physicians, psychiatrists, or social workers. Most were nondirective, emphasizing group discussion and the disclosure of feelings. The goals of such programs were to minimize individual feelings of isolation and difference; demonstrate universality of feelings, thereby diluting their intensity; provide information, emotional expression and support; encourage the formation of friendships and participation in group activities. These groups generally seemed to be effective in channeling parental hostility and diffusing parental guilt, but measures are rarely reported and no control procedures were utilized. These programs rarely derive from an empirical or theoretical base, and are rarely systematically evaluated. Thus, it becomes difficult to assess whether significant improvement has occurred in the family, and if so, why.

One article of particular interest cross-culturally dealt with factors interfering with the successful implementation of intervention programs aimed at physically handicapped Mexican-American children and their families [195]. These included (1) strong family pride, rejecting the help of 'outsiders', (2) the need for approval of any treatment plan by the priest or other religious leader, (3) the machismo ethic, which often interpreted disruptive, maladaptive behavior in male children as normal 'masculine' behavior and thus not in need of treatment, (4) family values encouraging child passivity, which reduced the affected child to an inappropriately dependent state, (5) superstition and lack of knowledge about medical and rehabilitation technology and (6) the potential negativism of extended family and friends. The article stressed the importance of a home-centered approach.

FAMILY COPING WITH CHILDHOOD CANCER

The initial parental reaction reported is one of shock and disbelief. The period after diagnosis is

characterized by confusion, anxiety and realistic fear; insomnia, sleep disturbances and anorexia. The period of remission appears to be characterized by ongoing strains in daily living, as well as behavioral and academic problems of siblings [196]. In the initial phase, other parental responses include loss of control, physical distress, depression, inability to function, anger and hostility. Blame and guilt are other common reactions, although guilt was not characteristically manifested by prolonged and exaggerated feelings of wrongdoing, but was more usually a transient phenomenon. Anticipatory grief reaction occurs, characterized by intellectualization, irritability, depression, somatization, denial, frenzied activity and worry about the circumstances in which the child will die. After the child's death, there was no unusual incidence of somatic complaints or minor illnesses in parents reported [197, 198].

In a University of Kansas Medical Center Study [199], it was found that while families of child cancer patients had extremely high marital stress levels (higher than hemophilia parents, for example, and approaching couples in marital counseling) the incidence of person-year divorce rates was actually less in the study group than in the general population. Death of the sick child did not seem to be associated either with divorce or elevated marital stress scores. Couples in the study group were characterized by feelings of low self-esteem, helplessness and strong dependency needs. Also noted were discomfort on the part of one spouse and conflict between marital partners over social contacts.

Several parental reports claimed that the child's illness either improved the marital relationship or did not have any effect [200]. In only a few cases did subjects report any serious marital friction resulting from the illness. Subjects also reported no change in their attitudes toward religion. They did acknowledge a more protective attitude toward remaining children. During the terminal phase of the child's illness, sleep difficulties and loss of appetite were common, as was a preoccupation with the sick child. Somatic complaints were infrequent, but 33% reported some difficulty in performing their routine duties during this period. During this phase, some parents felt ambivalence and in implicit ways rejected their child. Signs of an incomplete grief process included: (1) refusal to dispose of personal effects; (2) severe, unremitting feelings of depression; and (3) fear of the mourning process by refusing to think of the loss and/or attempts to replace the lost loved one. Many parents looked forward to their child's death, and experienced relief as well as grief at the actual death. Thirty-three percent of this sample reported the time of diagnosis most difficult, while 33% reported the death as the most difficult time and another third felt these two periods were equally difficult [201].

The family dimension in childhood cancer has been treated with increasing importance [202]. There is awareness of the child as part of a complex biopsychologic system, and an acknowledgment that the entire family system requires treatment, not only the child. Predictors of successful family coping include the stability of the marital unit and the family's ways of dealing with recent crises.

Various coping responses in the child triggered by

cancer have been identified [163]. These include quietude, withdrawal, denial of seriousness, aggressiveness, acting-out. It has been pointed out that the child's response is generally influenced by the family's reaction. There appears to be a maturational aspect to the fear child cancer patients experience [203]. Younger children were most threatened by maternal separation. Children aged 6-10 were most fearful of physical injury, while those aged over 10 were most fearful of death itself. One survey reported no noticeably rebellious behaviors in affected children. Similarly, no noticeable effect on school performance was noted. Parents felt that, except for relapse periods, their children behaved the same as they had prior to contracting the disease. However, other studies observed the child to be openly rejecting of parents, partly because the parents had been unable to protect the child from pain, and partly because the parents were a safer target for aggression than the hospital staff.

Numerous effects on siblings of cancer patients also have been noted, including resentment at extra attention and restrictions on family life. At the death of the affected child, many siblings displayed what has been labeled a 'short sadness span', resuming apparently normal behavior in a relatively brief amount of time. During the illness itself, siblings manifested physical and behavioral problems, enuresis, headaches, poor school performance, depression, tearfulness, separation anxieties, disturbed eating habits and persistent abdominal pains. Several felt jealousy toward the affected child due to parental attention. Siblings often felt responsible for the death, or feared they would also die of leukemia. One study showed that after the death of the affected child, more than one-half of the siblings required some sort of medical consultation lasting longer than one year [200]. Another study of childhood cancer [204] showed that siblings experienced even more psychological distress than patients in terms of perceived social isolation, perception of parents as overindulgent toward and overprotective of the sick child, concern with failure and fear of confronting parents with negative feelings. In terms of general anxiety and perceived vulnerability to illness siblings and patients reported similar levels. However, another study based on parental report indicated 70% of siblings were 'back to normal' within one week of the child's death [205].

Coping with cancer may take a variety of forms. In one study, close and intimate support from friends was associated with longer than predicted survival rates [122]. Many parents also reported the helpfulness of discussion groups to ease guilt and to clarify the normalcy of their feelings. Parents most appreciated discussing their feelings about the leukemic child, as well as financial advice [200]. Several articles emphasized the importance of coping through information accumulation and processing. Coping often took the form of focusing on details, rather than on the more general (and tragic) picture, denial and motor activity. Coping after the death of the child included an opportunity to relive the experience over and over, until finally acceptance occurred [196]. Often, fathers coped by absenting themselves from families. Parents sometimes turned to each other for support, but sometimes were too overwhelmed by

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their individual grief to give much support to their partner. Persistent denial seemed to characterize the outer circle of relatives, rather than the inner circle of the family itself, with the phenomenon of "concentric circles of disbelief" being noted [197]. Parents tried to treat the child normally, and to live day-by-day. Coping with a sense of guilt came from contact with other mothers on the ward, also through rational learning, and ventilation of guilt feelings. It was felt that the mother's participation in the care of her child facilitated resolution of guilt and denial [203].

A study by Kaplan [139] estimated that 87% of the families they studied failed to cope successfully with the diagnosis of a leukemic child. School difficulties among healthy siblings, divorce and illness occurred frequently. Adaptive coping in this situation seemed to be characterized by an understanding of leukemia as a serious, ultimately fatal illness involving remissions and exacerbations; an acceptance of the child as chronically sick instead of normal; and a period of shared family mourning and mutual consolidation. Maladaptive coping, on the other hand, was characterized by a persistent denial of the reality of the diagnosis; a lack of open communication in the family, and the feeling that knowing will lead to disaster; an inhibition of emotion out of fear of the consequences of emotional expression; flights into activity, which only increased the family's burdens; hostile reactions to members of the health center staff; and inappropriate feelings of being unable to cope with the child's care. Another phenomenon, which Kaplan labeled discrepant coping, was identified, in which parents took opposing positions in terms of their emotional responses, decisions about treatment, and decisions about whom to tell and how. Discrepant coping produced dishonest communication or prevented communication; prohibited or interrupted individual and collective grieving; and overall, tended to weaken family relationships. Finally, Kaplan stressed the importance of phase-related coping tasks, tied to diagnosis, remission, relapse, and the terminal phase, which must be resolved in proper sequence to enhance the success of the overall coping process.

FAMILY COPING WITH DEATH

Families respond to death of a child based on their own dynamics and homeostatic mechanisms; the assignment of family roles; the need to maintain secrecy around sensitive information; defense mechanisms and affective reactions [206]. It has become increasingly clear that in the case of a dying child, the family's emotional pain must be attended to [207]. Families respond to death with a combination of guilt, anger, hostility, shock, and a period of grieving [208]. Bowlby has identified three stages of mourning [209]—(1) protest and denial, (2) despair and disorganization and (3) reorganization—which families experience. Other common reactions include confusion, depression, despair and overly controlled behavior. Sudden death prolongs feelings of shock and disbelief, as the family does not have the opportunity to work through other stages of the grief reaction. However, with a chronically ill child, two losses are involved, one at the time of diagnosis, and the other at the time of actual death [210]. Fathers tend to maintain more

overt calm, yet feel dazed, preoccupied, heartsick and cry when alone. Parents often exhibit a surface control, in an effort to produce appropriate behaviors [206]. They may act warmly and supportively toward the dying child, or may withdraw or may engage in inconsistent indulgence. This inconsistency may frighten the child, who reacts by testing parents, which in turn provokes parental anger, then guilt. Parents sometimes manifest phobic reactions to death. They tend to be overly restrictive, protective and to infantilize siblings. Parents also may attempt to replace the lost child with another sibling. Severe anxiety states, insomnia, nightmares and incessant talk about death and the dead child, auditory hallucinations of the dead child and rage-filled agitation are not uncommon [211]. The death of a child can be disastrous if the function of the child was to camouflage existing conflicts in the family.

Siblings also need attention at this time; otherwise, they may regress, experience somatic symptoms, develop fears of death, isolate their feelings, or express anxiety in other ways. A study of siblings under psychiatric care for pathologies related to the death of their brother or sister [212] emphasized a feeling of responsibility, whether objectively justifiable or not. (Many of these deaths were related to accidents which did in fact involve the siblings.) Siblings can acquire distorted concepts of illness and death, which exaggerate their vulnerability in the real world. Like parents, siblings may also develop death phobias and an association of physicians and hospitals with death.

In terms of coping, there is some evidence that families able to deal with death openly and personally may experience less physical illness than those who do not. Families that coped well with death were found to have more open internal communication, discuss and make realistic plans, express feelings of sadness and loss as well as anger, guilt, and relief and basically attempt to deal with stress rather than deny it [213].

The inability to cope with death may be characteristic of an entire family. Death may become a family pattern in which members collude to avoid confrontation. Family functions of the deceased individual must be redistributed among other family members. In incomplete adaptation, some families may encourage a particular member to assume the role of the deceased as though he were still alive. Unresolved grief reactions have a deep influence on the personality, and may result in later marital discord, behavior problems in children, irrational behavior in parents and mental illness.

IMPLICATIONS FOR HEALTH CARE

The clear interaction between family and illness, the potentially devastating impact of serious illness in the child on the entire family unit, and the power of family coping to positively or negatively influence eventual outcome of the illness episode all point to significant implications for the delivery of health care to child patients. These implications may be conceptualized as occurring on an awareness level and on an implementation level; on an individual level and on a systems level. Figure 2 illustrates the interactive nature of this model.

Awareness		Implementation
Individual	Personal Consciousness	Personal Action
System	Systemic Attitudes	Systemic Change

Fig. 2. Individual and systems implications of a family-oriented approach to health care.

For the individual health care provider (physician, nurse, health psychologist, social worker, health educator, etc.) an important implication has to do with developing a family-focused way of viewing concepts of health and illness. Once it is understood that the family plays such a critical role in a variety of health care outcomes, adopting an attitude of attention to and inclusion of the family in the provision of health services becomes much easier and more natural.

Attitudinal changes, however, also need an action outlet. Again considering only the individual health care provider, several action implications become evident. One aspect of implementation would be developing the tools and skills to assess family coping resources and responses. Several attempts have already been made at family assessment schema [214-219]. Patient charting could also be arranged to reflect a family orientation. From a preventive medicine standpoint, physicians and other health care providers could be more sensitive to anticipating psychological and physical problems in family members other than the identified patient; to anticipating interactions between family members known to be statistically or clinically associated with increased family distress and dysfunction; and to anticipating points of particularly high stress during the developmental family life cycle. The physician should also have basic skills to intervene therapeutically with families in the sense of educating them to increase the range and flexibility of their adaptive coping responses.

It is obvious that in order to produce physicians and other health care providers skilled in these areas, major systemic changes would also have to occur. One major area of change might be in the field of medical education, which currently pays scant attention to instruction about family process, structure, and function. A family-oriented approach to health care is not simply an attitude of mind, but requires a specialized knowledge base, which is at present neglected in most areas of medical education.

In addition to education changes, other systemic changes might include (1) structural changes in hospitals and other in-patient facilities encouraging the current trend toward family involvement with the hospitalized child, (2) attitudinal and procedural changes among staff and hospital personnel to allow the family more of a traditional caretaking, rather than a guest, role in such facilities, (3) recognition among the medical profession of the importance of the family doctor as the coordinator and supervisor of all aspects of medical care concerning the family unit and (4) changes in insurance policies to make treatment (preventive or non-pharmacological) of family members less of a family financial burden.

Clearly, the above represent only a few brief illustrations of the wide-ranging implications of family

ramifications of illness in a child. In particular, a concept deserving greater attention is that physicians have at their disposal a largely underutilized resource, the patient's family, which often works at cross purposes to therapeutic medical aims, and yet, with increased knowledge, could be mobilized efficiently and productively as a crucial support system for medical intervention. Many experienced, and all good doctors intuitively know this already, and are able to involve the family in their treatment approach with beneficial results for both patient and family. What is still needed is additional research and clinical investigation to clarify concepts such as 'family' coping, 'adaptive and dysfunctional' coping, and to tie these to specific behavioral and cognitive skills which the physician can integrate into medical practice. In this way, a critical dimension of the art of medicine, the awareness of the family as patient, will begin to move into the realm of science.

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