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ABSTRACT

This literature review provides information to help in building a model of family caregiving for children with emotional disorders, focusing on the elements of stress, coping, and appraisal. Because literature on families' perceptions, use of resources, and coping with a child with an emotional disorder is nonexistent, the review uses the literature on family responses to a child's chronic illness or disability. This literature is extensive and cuts across numerous professional domains and academic disciplines. The review describes two conceptual models that provide a view of family response to stress (R. Hill's ABCX model and R. Lazarus and S. Folkman's model). They serve as the basis for synthesizing a tentative but more comprehensive model. The proposed model is specified in terms of constructs or latent variables grouped into three categories: antecedent variables, mediators, and adaptational outcomes. In building a comprehensive model, the review identifies a range of factors, some of which some are given characteristics of the family, child, or community and others are changeable characteristics that may vary as families attempt to deal with their child's illness or disability. With a focus on the conceptual and operational definitions of the major identified mediators, the review looks backwards in the stress process to identify causal antecedents and forward in an attempt to specify adaptational outcomes that capture desired end states. (Contains approximately 130 references.) (JDD)

# Building a Conceptual Model of Family Response to a Child's Chronic Illness or Disability

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## OVERVIEW

The role of the family in the care of children is well understood. Yet some children present special challenges for their family caregiver. Parents who raise more than one child are acutely aware of the differences between children. Even with the same biological parents and the same family environment some children are "easy" to raise and some are "difficult." The presence of an emotional disability adds an additional complexity. The reason for the disability is frequently as inexplicable as differences between "normal" children in the same family. However the task of caring for a child who for no apparent reason becomes violent, hallucinates or becomes totally withdrawn places special demands on the caregiver.

The family caregiver of a child with an emotional disorder faces great challenges and barriers to performing traditional roles. When a child requires 24-hour supervision and management of behavior it is difficult to go grocery shopping, attend school functions important to other children in the family or maintain an intimate relationship. With violent uncontrolled outbursts there are serious threats to the child, other family members and the caregiver. The possibility of long term dependence may foster feelings of resentment and guilt. Giving up may become increasingly appealing.

The important role that families play in caring for children with emotional disabilities is more than a value statement. It is a statement of reality. Families care for more children with disabilities than do other institutions (Lourie, 1987). Social policy and fiscal conditions in most states result in controlling or reducing out-of-home placement services, so that the primary responsibility for care of a child with a disability does not rest with professionals but with the child's parents, usually with the mother (Hobbs, 1975). Society needs the good efforts of parental caregivers. Yet the view of many parents with regard to services seems to be that they are impersonal, slow, cumbersome and insensitive (Byrne & Cunningham, 1985).

The purpose of this literature review is to provide information that will help us understand the reality of families caring for a child with an emotional disorder. The intent is for this review to inform family-centered research for families of children with emotional disabilities. More importantly the intent is to contribute knowledge that will assist policymakers in developing services that help families care for children with emotional disorders.

The focus of this review is on families and the multitude of variables and factors that contribute to families' perceptions, coping, use of resources and the consequences to the family of caring for a child with an emotional disability. The amount of literature on families is huge. The literature on families of children with emotional disorders is much smaller and is dominated by "guilt by association." The dominant model is to measure a set of characteristics of the child, a set of characteristics of other family members, correlate the findings and imply a causal relationship. The literature on families' perceptions, use of resources and coping with a child with an emotional disorder is nonexistent. Consequently this review uses the literature on how families respond to a child's chronic illness or disability. This literature is extensive and cuts across numerous professional domains and academic disciplines (Knafl & Deatrick, 1987). Although caring for a child with an emotional disability may be a very different subcategory of concern, it is our judgment that this literature is the most useful as a starting point.

This research draws from a body of sociological and psychological theory dealing with concepts such as control, self-esteem, causal attribution, stress and coping, anxiety, and cognitive adaptation. However, despite the volume of research and prominent theoretical underpinnings, this work has done little to contribute to the basic understanding of the complex interrelationships between child, family and community resources and services and how these relationships can be fostered to support the family in performance of its traditional roles. Regarding the utility of this research, Knafl and Deatrick observe that:

> Ideally, this body of research should provide a rich data base for practitioners working with families in which there is an ill or disabled child member. In reality, it presents an overwhelming and confusing body of information characterized by competing hypotheses, conflicting findings, and tentative conclusions. (p.300)

Numerous factors have contributed to this situation. Different studies are predicated on different underlying assumptions regarding the nature of the illness experience and the family's response to it (Knafl & Deitrick, 1987). Research that has attempted to study the impact of the child's illness or disability on the family has been found to be biased toward dysfunctionality. Turnbull, Behr, and Tollefson (1986) have noted that the assumption by researchers that the impact of mental retardation is pervasively negative has led to designs in which the possibility of positive effects is virtually unexplored and that when a result suggestive of a positive outcome is observed, it is either attributed to methodological flaw or to socially desirable responding.

The diversity in theoretical perspectives has been a contributor to confusion especially when writers within a particular field have made little or no attempt to be integrative. For example, the 1984 book *Stress, Appraisal and Coping* by Lazarus and Folkman, from psychology, contains no mention of the work done from a more sociological perspective on family stress (Hill, 1949; McCubbin, Sussman & Patterson, 1983). Behr (1989) has only recently provided an integration of work on cognitive adaptation in the study of adjustment to threatening events, and the early work of Hill and more recent models by McCubbin and Patterson.

A third source of the disarray is the lack of well articulated comprehensive models. Most studies have been descriptive, focusing narrowly on one or two components in what is generally regarded as a complex multi-dimensional process (Byrne & Cunningham, 1985; Crinic, Friedrich, & Greenberg, 1983). With regard to the statistical bias that is known to result from model specification error (see for example: Pedhazur, 1982, pp. 225-230), Turnbull and her colleagues provide the following characterization of the state of research on families with children with mental retardation:

> The typical design, utilizing a small sample and perhaps one or two independent or control variables, is inadequate to account for this complexity and may yield results that are conflicting or nonsignificant (Turnbull, Behr, & Tollefson, 1986).

Even purely descriptive studies are of limited utility given the conceptual ambiguities and lack of uniform measurement that characterizes the field. Conceptual ambiguities mirror and contribute to the confusion that exists. "Stress" is variously conceptualized as a cause and an effect. It is also defined as a process (Lazarus & Folkman, 1984). "Cognitive coping," "appraisal" and "perception" are used interchangeably by some authors while others perceive distinctions. Adaptation appears to be an outcome in one model influenced by coping but upon closer

examination seems to be defined as successful coping (McCubbin & Thompson, 1987). The lack of conceptual clarity, and diversity in theoretical perspectives and assumptions virtually guarantees lack of consensus in measurement approaches and methodological approaches. This problem has been identified by various reviewers in the field (McDonald-Wikler, 1986; Lazarus & Folkman, 1987; Behr, 1989).

Prompted, at least in part, by the move toward deinstitutionalization and the increasing role that the community plays in providing treatment, there has been a call to involve the family more systematically and formally in the long-term care and treatment of the child, regardless of where the child may reside. More systematic efforts have also evolved to identify roles and activities on the part of professional helpers that will reinforce and support the family in providing care for the child. This research discards the assumption of homogeneity among families and the assumption that a "pathological response" is inevitable. In this new line of research, attempts are made to look more comprehensively at factors influencing family functioning to describe which families are most vulnerable, identify unmet service needs and strategies to overcome them, and, in its most radical departure, stresses the normality and strengths of these families. The research seeks to describe the potential psychological, material and social resources such families use and the coping strategies they evolve (Byrne & Cunningham, 1985).

This review of theoretical and empirical literature on families with children with chronic illness or disabilities is intended to support these trends by:

1. Identifying the central underlying constructs that current research and theory suggest are crucial to understanding family caregiving systems;

2. Comparing and contrasting nominal and operational definitions for these constructs; and

3. Relating these constructs in a comprehensive model of family caregiving based on a synthesis of major theories and empirical research.

The essential task in this effort is to impose a degree of order on a disorganized body of work. Some might argue that an attempt in this direction is doomed from the start; that the confusion in the literature reflects the complex interactions of dynamic forces inherent in the operation of an ongoing process like a family system; that tight definitions and causal ordering cannot be imposed on such a system. While acknowledging the complexity of family caregiving systems and the limitations of research methodologies, the authors believe that current knowledge in this field can be processed in such a way that existing ambiguities and conflicting views can at least be identified and framed in a way that will permit systematic ongoing exploration and improved understanding. The authors believe that much of the existing confusion results from a failure to integrate theories and studies in a systematic and disciplined manner guided by an explicit conceptual model.

This review is grounded in several assumptions that serve to both direct activities and guide interpretations. There is a belief in the ability to articulate, test and further refine a causal model which "explains" the operation of family caregiving systems and can guide research and practice interventions. In building such a causal model, the importance of family and child descriptors and identified processes are a function of their role in determining desired outcomes. Implicit in the focus on outcomes is the view that some descriptors or processes that may exist (of theoretical

interest) are of no interest within an applied caregiving model. The search is to identify factors that might be manipulated or supported in ways that could lead to better family and child well-being.

The final assumption relates to the nature of the outcomes the model seeks to explain. From the perspective of the authors and consistent with a growing body of literature, these outcomes are expected to be both positive and negative. Some families appear to be destroyed by caring for a child with an emotional disability while others appear to be strengthened.

If successful, this review will be of use to families, to professionals, and to researchers. The need to understand how something works in a causal sense is central to each of these groups. All are vitally interested in "making things better" and must therefore be interested in cause and effect relationships. This review was undertaken in the hopes of obtaining and promoting a better understanding of such relationships in the family caregiving system, thereby contributing to "making things better" for the families and children involved.

The strategy for the review employs three steps. The first involves a search for existing conceptual models that provide a more comprehensive view of family response to stress. Our search, guided in part by the work of Behr (1989), led to the identification of two models which, despite their commonalities, appear to have developed rather independently. These models are described in the following section and serve as the basis for synthesizing a tentative but more comprehensive model.

The model is first specified in terms of constructs or latent variables. These constructs are grouped into three categories: (a) antecedent variables (exogenous), (b) mediators (endogenous variables), and (c) outcomes (endogenous variables). With regard to each of these endogenous constructs the review addresses three questions:

1. How do various writers conceptually define the constructs?

2. How are the constructs operationally defined (i.e. measured)?

3. What antecedent variables have been found to be related?

In reviewing the constructs at the conceptual and operational levels, inconsistencies and ambiguities are identified for individual writers and comparisons are made between different theorists and researchers. The intent is to arrive at clearer and more concise definitions and to identify appropriate tools for measurement.

The search for antecedent variables provides a framework for testing the tentative model. That is, by looking backwards from each of the endogenous variables we are able to: (a) discern the degree of empirical support for the hypothesized exogenous variables in the model, and (b) identify predictive variables that are not captured in the tentative model.

The critical review of endogenous constructs addressing each of the three questions listed above leads to a reformulation of the comprehensive model. The reformulated model involves modified and new constructs and paths between these variables. The reformulated model includes specific indicators for each construct.

This review and the resulting model are expected to support practitioners, researchers and parents in their work with families with children with chronic illness or disability. In building a comprehensive model the review will identify a range of factors, some of which are given characteristics of the family, child, or community, and others which are changeable characteristics that may vary as families attempt to deal with their child's illness or disability. For example, factors such as the sex of the child, marital status of the parent, and population density of the community of residence can all be viewed as a fixed set of circumstances that make up a given family's situation; whereas, policy-relevant variables such as availability of services, use of services, coping strategies, and perceptions of the disability can be viewed as variable actions or states that can change as the family learns to deal with its situation and existing systems are made more responsive to family needs.

The identification of both given and changeable characteristics is important for administrators, practitioners, family advocates and the families themselves. Given characteristics can be used to identify unmet needs and for the targeting of special intervention efforts. Changeable characteristics can be manipulated to maximize positive outcomes for these families and children. In this way it is expected that the development and testing of a comprehensive family caregiving model will contribute to the well-being of families and children with a chronic illness or disability.

## EXISTING MODELS

In this section a description is provided of two models that attempt to identify and relate the various factors that influence individuals and families dealing with "crisis" or "stress." The two models are selected because they dominate the current family research and, while concerned with the same phenomenon, they have developed quite independently within different academic disciplines. The models also attempt to be rather inclusive in their conceptualization of the "stress and coping" process and both have strongly influenced theory and research in the field. The intent in this section is to provide a description of the salient features of the models that have relevance to the process of family caregiving for children with chronic illness or disability. A more complete analysis of the components of these models is provided in subsequent sections which also incorporates the work of other researchers and theorists.

The first model developed as a research framework in the field of sociology. Hill (1949, 1958) is credited with the original formulation of this family crisis model known as the ABCX model. This model has undergone significant reformulations with the most notable recent versions being the Double ABCX (McCubbin & Patterson, 1982) and the T-Double ABCX (McCubbin & McCubbin, 1987).

The second model has grown out of the stress literature in psychology and social psychology. It is perhaps best exemplified, particularly when searching for more comprehensive models, in the work of Lazarus and Folkman (1984). Not surprisingly this field has focused more on the cognitive aspects of stress and coping and has only more recently expanded to include other theories and to identify other factors and their roles in this process. While Hill's early work and the subsequent versions of his model recognize the cognitive process as the "C" factor, labeled "perception," research based on this model has paid limited attention to the importance of perception and has not clearly distinguished perception and coping.

Unlike the Hill model, Lazarus' stress model does not specifically apply to families but was developed with a focus on the individual. Neither model in its original form focuses on family caregiving or on families with children with chronic illness or disability; however, both have been applied by researchers in this field.

## FAMILY STRESS AND COPING MODELS

In Hill's (1958) formulation, Factor A, the stressor event, inter-acting with Factor B, the family's crisis-meeting resources, interacting with Factor C, the definition the family makes of the event, produces Factor X, the family crisis. This model is diagrammed in Figure 1 where one can note that the pre-crisis factors (the stress event, family resources and definition of the event) are hypothesized to interact in a nonrecursive manner to determine if a crisis will result and, if so, the extent of the crisis. This formulation highlighted two areas that had previously been overlooked -- the way families define events and their resources for coping with these defined events. Also, by attempting to explicate the process by which families respond to stress, Hill drew attention to the variance which exists in crises with some being more severe than others.

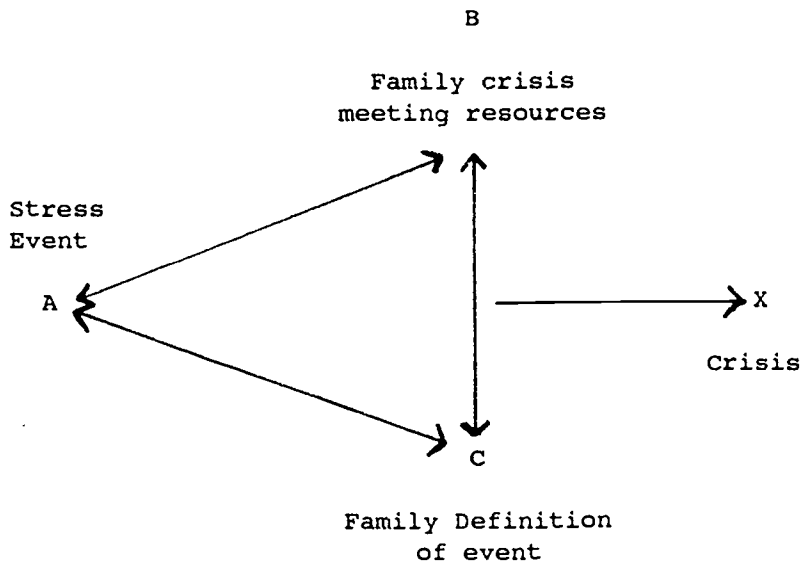


Figure 1. ABCX Model (Hill, 1949)

McCubbin and Patterson (1982) expanded on the theoretical foundations established by Hill's model. This line of research recognized the interaction of stress, coping and adaptation and proposed a conceptual formulation that incorporated these additional factors. Like Hill's original work, which grew out of the study of families' reaction to the stress generated by separations and reunions associated with World War II, the McCubbin and Patterson refinements resulted from a longitudinal study of families with a spouse or father who was held prisoner or was unaccounted for as a result of the Vietnam War. This "crisis" context has influenced the conceptualizations of both the stimulus and response in these models.

In McCubbin and Patterson's work, the original model developed by Hill is extended by tracking family process not only before but also after the stressor event (McCubbin et al, 1980; McCubbin & Patterson, 1981, 1982, 1983). In Hill's framework, a family, when confronted with a particular stressor, reacts to reduce the stressor based upon their resources and their perception of the event. While Hill conceptualized stressors as both normative (expected over the course of life) and nonnormative (sudden and unexpected) both were expected to produce crisis.

McCubbin and Patterson (1982) extend this analysis beyond the point of crisis, recapitulating the ABCX Model in response to both the original stressor and the crisis itself. In this model the family experiences not only the original stressor but also an accumulation of demands. Concerned with family adaptation, McCubbin and Patterson's model conceptualized the response of families to the stressor as phases of family adjustment, and family adaptation. According to them the family can accumulate three types of stressors during a crisis: (a) the initial event; (b) those that are a result of changes in the family's life and experiences; and (c) those that are a result of the family's attempts to deal with their problems. In this way stress and the changes resulting from it are seen as an ongoing process for the family that could possibly lead to positive outcomes. A schematic diagram of the Double ABCX Model of Family Adjustment and Adaptation (McCubbin & Patterson, 1983) is shown in Figure 2. The major contribution of this reformulation is the labeling of the interaction of factors ABC as "coping" and the introduction of the concept "adaptation" to describe the family adjustment over time. Adaptation, in this model, appears to be an outcome criterion denoting a certain level of functioning achieved over time through the adjustment process (Behr, 1989). However, adaptation is not clearly defined. Closer examination of operational measures (provided later) suggests that adaptation is "successful coping." Distinctions between adaptation and adjustment appear to blur as well when "indices of positive family adjustment" are defined to include the "areas of family satisfaction, marital satisfaction, child development satisfaction, family physical health, emotional health, and community satisfaction, as well as overall family well-being" (McCubbin, Thompson & Pirner, 1986).

The T-Double ABCX model of family adjustment and adaptation (McCubbin & McCubbin, 1987) introduces four additional factors:

> Factor V, family vulnerability -- this refers to how the family is organized and the nature of their interpersonal dynamics at the time the event takes place. It is determined by how many demands the family is already dealing with and by the particular life cycle stage the family system is in.

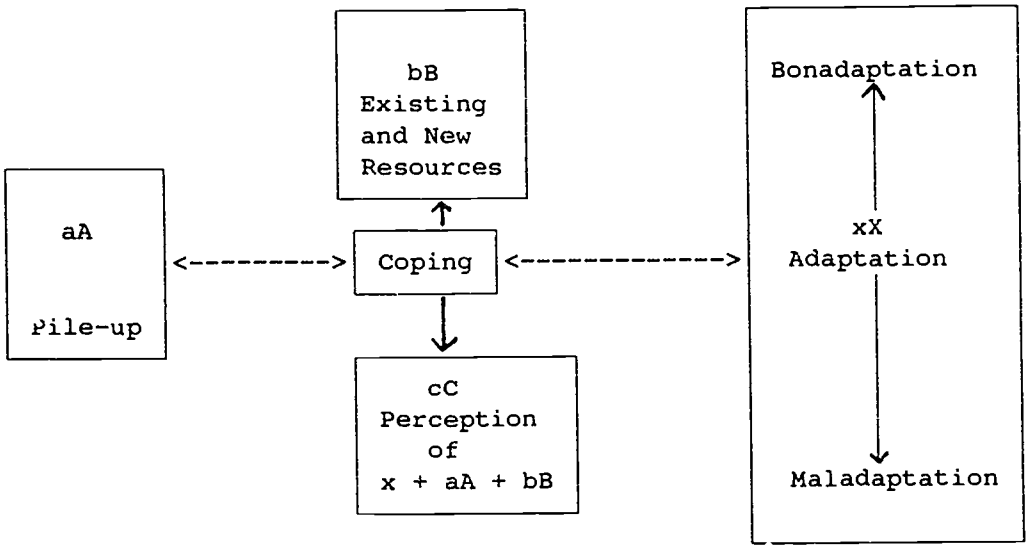


Figure 2. Double ABCX Model (McCubbin & Patterson, 1983)

Factor T, family typology -- represents a profile of family functioning. They define five typologies for their model: (a) balanced families; (b) regenerative families; (c) resilient families; (d) rhythmic families; and (e) traditional families.

Factor PSC, adaptative coping -- represents the way the family acquires and allocates the resources they need to meet the many demands made on the system. The family is seen as a resource exchange network and the action that facilitates this exchange is defined as coping.

Factor R, family regenerativity -- replaces Factor V in the adaptation phase and is determined in part by the pile up of demands already present in the family system at the time of the crisis and by the new demands created by the crisis event or transition.

The adjustment phase in this model is diagramed in Figure 3. McCubbin provides the following brief description of this process:

> The level of family adjustment and/or the family's transition into crisis situation (X) (and into the adaptation phase or exhaustion) in response to a stressor event or transition is determined by -- A (the stressor event or transition and its level of severity) -- interacting with the V (the family's vulnerability determined, in part, by the concurrent pile up of demands -- stressors, transitions and strains and by the family's life cycle stage), interacting with T (the family's typology -- regenerative, resilient, rhythmic, balanced etc.), interacting with B (the family's resistance resources) -- interacting with C (the appraisal the family makes of the event), and -- interacting with PSC (the family's problem-solving and coping responses to the family situation including the demands created by the stressor as well as the stressor event/transition itself) (McCubbin & McCubbin, 1987, p.4).

The adjustment phase transitions into the adaptation phase diagrammed in Figure 4. This process closely parallels the adjustment phase as described below:

> The level of family adaptation (XX) and/or the family's transition back into a crisis (or exhaustion) in response to a crisis situation is determined by -- AA the pile-up of demands on or in the family system created by the crisis situation, life cycle changes and unresolved strains -- interacting with R the family's level of regenerativity determined in part by the concurrent pile-up of demands -- stressors, transitions, and strains -- interacting with T- the family's typology -- resilient, rhythmic, balanced etc.), -- interacting with BB the family's strengths (the family's adaptive strengths, capabilities and resources) -- interacting with CC the family's appraisal of the situation (the meaning the family attaches to the total situation) and CCC the family's Schema (i.e. world view and sense of coherence which shapes the family's situational appraisal and meaning) -- interacting with BBB the support from friends and the community (social support), interacting with PSC the family's problem solving and coping responses to the total family situation (McCubbin & McCubbin, 1987, p. 14).

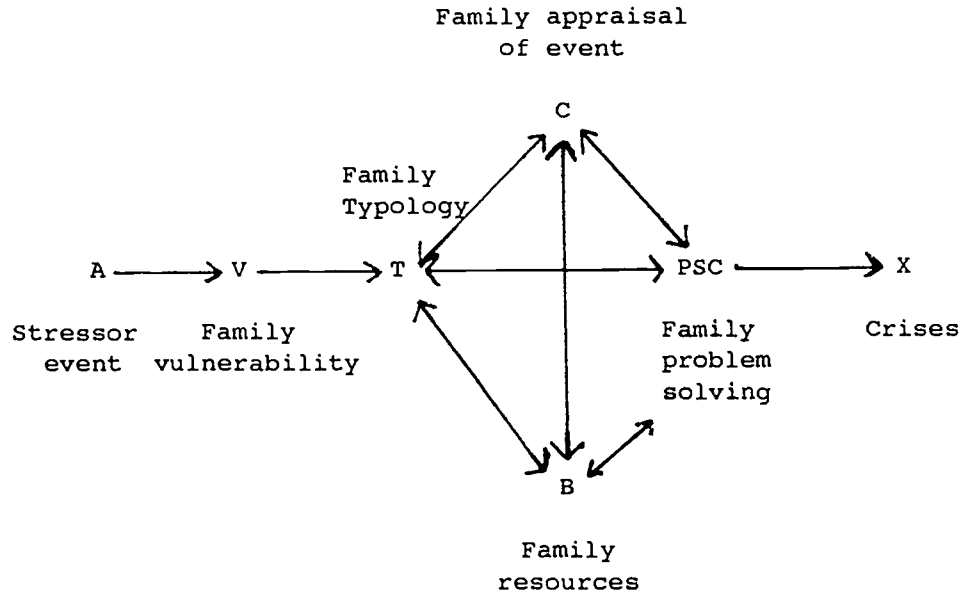


Figure 3. Adjustment Phase of T-Double ABCX Model
(McCubbin & McCubbin, 1987)

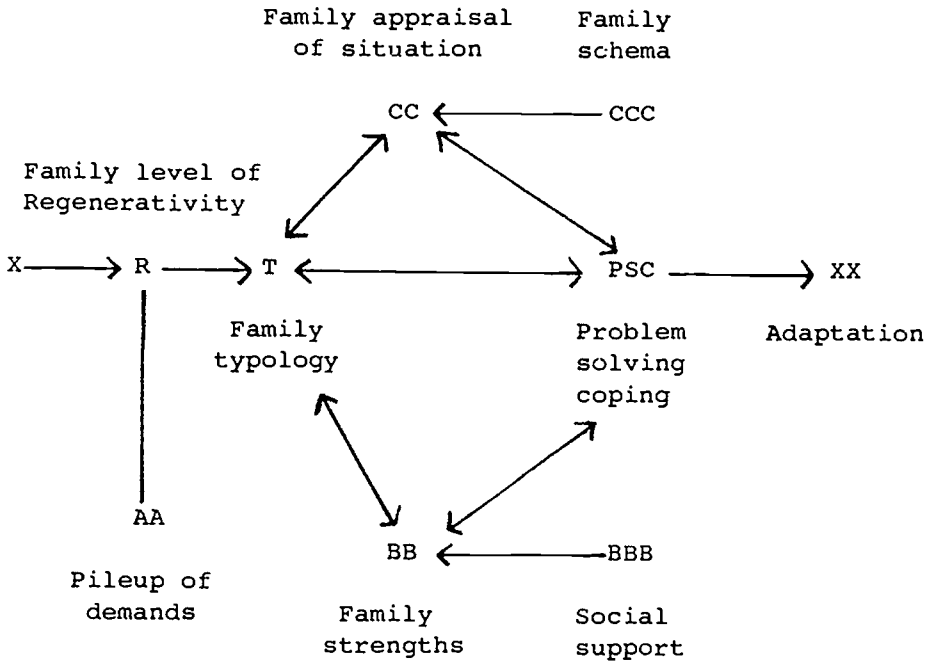


Figure 4. Adaptation Phase of T-Double ABCX Model (McCubbin & McCubbin, 1987)

The original model of Hill and the extended models formulated by McCubbin, et al., provide a framework for tracking the family process in response to a stressor life event. They are useful in their attempts to identify the major factors at work in this process and the more recent work of McCubbin begins to recognize and identify outcomes of this process. Similarly the models have evolved to realistically view the periodic eruption of family problems as a "normal" phenomenon, and implicitly define the family as an active agent of its destiny.

The major shortcomings of the models derive from ambiguous or tautological definitions for the central constructs and unclear causal linkages between these constructs. In particular there is a failure to separate cognitive processes from behaviors and behaviors that are a response to stress from outcomes that are produced. Conceptual ambiguities such as these that contribute to difficulties in separating causal linkages are not the only source of confusion. Nor does it appear to be the case that these ambiguities are simply a reflection of a complex, human process.

Further discussion of conceptual ambiguities is reserved for later sections. A careful reading of the verbal descriptions provided by McCubbin of the adjustment and adaptation processes and comparison with the corresponding diagrams provides several examples of the causal ambiguities. Generally one-headed arrows are used in diagrams of this type to indicate direct causal paths while two-headed arrows indicate mutual causality. The descriptions of these relationships use the terms "determined" (one-way effect?) and "interacting" (two-way effect?) in an inconsistent fashion to describe the diagrammed relationships. For example, in the adaptation model, AA is described as interacting with R and T, with R "determined in part by the concurrent pile-up of demands" (AA). Following normal conventions, the relationships shown in the diagram would lead to the following simplified causal statement: X and AA cause R which in turn causes T. However, it is not possible to know if this is what the authors intended.

## STRESS, APPRAISAL AND COPING

Lazarus and Folkman (1984) trace the "stress concept in the life sciences" including a brief history and review of modern developments. Nowhere do they mention the work of either Hill or McCubbin. The body of work encompassed by Lazarus and Folkman is primarily concerned with the individual and with explaining individual differences in response to stress. Stress is defined as arising from "the relationship between the person and the environment, which takes into account characteristics of the person on the one hand, and the nature of the environmental event on the other" (Lazarus & Folkman, 1984, p. 21). They argue that stress is not a variable but a "rubric consisting of many variables and processes" and see as central to their purpose the specification of "antecedents, processes, and outcomes that are relevant to stress phenomena" (Lazarus & Folkman, 1984, p. 12).

Cognitive appraisal is seen as the critical concept explaining the judgment that a particular person-environment relationship is stressful. It is thus viewed as the central mediator or process variable in a "cognitive theory of stress." Three kinds of cognitive appraisal are identified: (a) primary appraisal - judgment that an encounter is irrelevant, benign - positive or stressful; (b) secondary appraisal - judgment concerning what might and can be done; and (c) reappraisal - based on new information from the environment and/or the person. The other major process or mediator variable identified by Lazarus and Folkman (1984) is "coping." Coping is defined as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal

demands that are appraised as taxing or exceeding the resources of the person" (p. 141). The authors identify how this definition addresses limitations of traditional approaches to the study of coping and stress, many of which apply to the work of Hill and McCubbin. Both models view coping at the conceptual level as a process rather than as a set of traits. For Lazarus and Folkman, coping requires a conscious effort that distinguishes it from automatized adaptive behavior. McCubbin does not appear to address this issue. By defining coping as *efforts* to manage, Lazarus and Folkman also reduce the problem of confounding coping with outcome which is evident in McCubbin's work. Finally, by using the word *manage*, Lazarus and Folkman attempt to avoid equating coping with mastery. In McCubbin's model, coping and positive adaptational outcome (bonadaptation) at times appear to be equivalent.

While McCubbin and Hill's models make no explicit mention of the role of emotion, Lazarus and Folkman include it in their discussion of the stress process. Their cognitive approach to emotion leads them to "say that those values, commitments, and goals that are engaged in a transaction influence how the person construes a situation, and hence the emotions he or she will experience" (Lazarus & Folkman, 1984, p. 284). Their view of the interaction of appraisal, coping and emotion is perhaps best articulated in their 1988 article "Coping as a Mediator of Emotion" in which emotion is described as arising initially from appraisal to influence coping efforts which lead to reappraisal and a new emotion. Emotion is thus conceptualized as an immediate effect arising from the mediating functions of appraisal and coping.

While Lazarus and Folkman provide an excellent critique of traditional approaches to the study of coping and address many of these limitations in their approach, some of the same problems seem to exist in their research. They are most successful in separating coping from adaptational outcomes. The major shortcoming derives from their inclusion of cognitive efforts in the definition of coping which results in a failure to separate coping and cognitive appraisal as unique constructs. Similarly, they refer to "emotion-focused coping" which tends to blur the distinction between coping efforts and contributing and resulting emotions. These definitional problems are addressed in greater detail in a later section. However, while a process perspective of coping complicates causal ordering, the authors are fairly clear in their statement that "coping is determined by cognitive appraisal" (Lazarus & Folkman, 1984, p. 157) and that "cognitive appraisals lead to specific emotion qualities" (p. 284).

Having identified the central mediators of stress, Lazarus and Folkman (1984) turn to the identification of antecedents and adaptational outcomes. Antecedent variables are divided into two categories: person factors, and environment factors. Commitments and beliefs are identified as the most important person factors affecting cognitive appraisal (p. 80). Identified properties of encounters (environment) that create the potential for (appraised) threat, harm, or challenge are identified as: novelty, predictability, event uncertainty, temporal factors (imminence, duration, and temporal uncertainty), ambiguity and timing of the events in relation to the life cycle.

Lazarus (1966) has tried to conceptualize stress as a general concept rather than a specific variable thereby avoiding confusing and conflicting definitions that include stimulus, response and outcome perspectives. However, in so doing, he indicates that it is also "appropriate to measure stress as either input, response, or strained relationship, as long as the one being measured is made explicit" (Lazarus & Folkman, 1984, p. 307). From this perspective one can see that the traditional definitions of stress or "stressor" as input are captured in what Lazarus and Folkman identify as environmental antecedents. Lazarus and Folkman are, however, critical of the use of

life events as a measure of stress which is a major part of the definition of the A factor (stressor event) provided by McCubbin and Patterson (1982). The life events approach, it is argued, has defects in its major assumptions, that change alone is stressful and that events must be major in order to create stress of sufficient magnitude to impair health. Furthermore, they find little empirical evidence of the power of life events approaches in predicting health outcomes (Lazarus & Folkman, 1984, p. 327). As an alternative they suggest the measurement of "ordinary daily hassles of living" and maintain that hassles appear to be better predictors of health outcomes. The effect of hassles on other adaptational outcomes appears to be unknown.

A particular strength of the work of Lazarus and his colleagues, from the perspective of this review, is that they view the prime importance of appraisal and coping processes in terms of their effects on adaptational outcomes. Much theory and research in this field, including the work of Hill, has lost sight of this linkage by focusing solely on the coping process. Process research of this type has few boundaries. The linkage to outcome provides a criterion that can be used to judge which aspects of a process are important. While not all research must be subjected to this criterion, when we strive to help families and to help practitioners in their work it is a central concern.

Lazarus and Folkman (1984) identify three basic kinds of outcome: functioning in work and social living, morale or life satisfaction, and somatic health. These long-term adaptational outcomes are not viewed as direct products of coping and appraisal but arise from the effects of these processes on the short-term outcomes of stressful encounters including: positive or negative feelings, quality of outcome of stressful encounters, somatic changes and acute illness. Of these three adaptational outcomes, health and morale appear to be the most clearly conceptualized and discrete. The discussion of social functioning is less compelling and appears to have some of the problems described in the above critique of McCubbin in that social functioning becomes "effective coping." Lazarus and Folkman are critical of sociological definitions of social functioning that tend to look at the fulfillment of various roles from a normative perspective and psychological definitions that look at satisfaction with interpersonal relationships and/or in terms of requisite dispositions and skills (Lazarus & Folkman, 1984, p. 183). However, they do not provide a clear alternative to these approaches.

The final step in the development of the Lazarus and Folkman model (1984) involves an interdisciplinary and multileveled perspective that adds to the psychological interpretation, the social and physiological (p. 306). All these components and perspectives are represented in the diagram shown in Figure 5.

The stress, appraisal and coping model of Lazarus and Folkman has several strengths. The explicit focus on person and environment is consistent with ecological approaches to research and practice with families and children. The definition of coping which includes both cognitive and behavioral components seems to reflect experience of families of children with chronic illness. The explicit emphasis on the outcomes of the coping process is also consistent with our orientation and intent. As is true in any developing area, problems remain. Cognitive coping and cognitive appraisal do not seem to be well distinguished. Recognition of the role of emotion in the process is a significant contribution yet distinguishing emotion which contributes to coping and that which results from coping is problematic. Finally, the systems perspective reflected in

Figure 5 recognizes the complexity of the multiple factors and dimensions while considering antecedents, processes and effects. However, deriving from this model a more precise description of the relationships between antecedent, processes, and effects, both direct and indirect, is problematic.

| | Causal Antecedents | Mediating Processes | Immediate Effects | Long-term Effects |
|---|---|---|---|---|
| SOCIAL ▲ | SES<br>Cultural templates<br>Institutional systems<br>Group structures (e.g., role patterns)<br>Social networks | Social supports as proffered<br>Available social/ institutional means of ameliorating problems | Social disturbances<br>Government responses<br>Sociopolitical pressures<br>Group alienation | Social failure<br>Revolution<br>Social change<br>Structural changes |
| ▼ PSYCHO-LOGICAL ▲ | Person variables:<br>values-commitments<br>beliefs-assumptions, e.g., personal control<br>cognitive-coping styles<br><br>Environmental (Situational) variables:<br>situational demands<br>imminence<br>timing<br>ambiguity<br>social and material resources | Vulnerabilities<br>Appraisal-Reappraisal<br><br>Coping:<br>problem-focused<br>emotion-focused<br>cultivating, seeking & using social support<br>Perceived social support:<br>emotional<br>tangible<br>informational | Positive or negative feelings<br><br>Quality of outcome of stressful encounters | Morale<br><br>Functioning in the world |
| ▼ PHYSIO-LOGICAL | Genetic or constitutional factors<br>Physiological conditioning-individual response stereotypy (e.g., Lacey)<br>Illness risk factors-e.g., smoking | Immune resources<br>Species vulnerability<br>Temporary vulnerability<br>Acquired defects | Somatic changes (precursors of illness)<br>Acute illness | Chronic illness<br>Impaired physiological functioning<br>Recovery from illness<br>Longevity |

Figure 5. Cognitive Appraisal Model of Stress and Coping (Lazarus & Folkman, 1984)

## TENTATIVE MODEL AND DEFINITIONS

Having reviewed two prominent models of stress and coping, we are now prepared to formulate a tentative model describing family response to the demands of caring for a child with chronic illness or disability. The specified model and definitions are tentative in that they represent a formulation prior to the conduct of a more extensive review of the theoretical work described above, various applications of these theories in the research on families with children with chronic illness or disability and the related work of other theorists and researchers. In formulating this model and conducting the subsequent review our goal is to arrive at a specification of the unique constructs of this caregiving process, to specify critical outcomes for these families and children and to identify critical factors that influence the process and outcomes achieved.

The formulation of the tentative model of family caregiving is diagramed in Figure 6. This model is consistent with both the Lazarus and McCubbin models in that it identifies three major stages in this process: antecedents, mediators and outcomes. Causality is expected to flow from left to right, that is antecedents to mediators to outcomes; however, the total effect of antecedents may not be entirely explained by the mediating process (i.e., there may be direct and indirect effects). The process by which mediators interact is left largely unexplained at this point.

### MEDIATORS

We focus first on the mediating process since this appears to be the most difficult to untangle and specify unique components. Three critical constructs: perceptions, coping, and emotions, are identified as part of the mediating process which determine how the family will deal with their child's disability or illness and the outcomes they will achieve. While complications exist in defining all three and their relationships, emotions would appear to be the most difficult to specify. The mediating process involves a cognitive (perception) and behavioral (coping) component. Their usage here is intended to provide a further separation of the thinking and doing processes than either the McCubbin or Lazarus definitions provide. The construct of perception closely parallels that of "appraisal" for Lazarus and Folkman and "Factor C" for McCubbin and Patterson. *Perception is defined as the cognitive process by which family members come to understand the causes and meaning of their child's condition and its implications for their own lives.*

Both "Family Stress and Coping" and "Stress, Appraisal and Coping" models include "cognitive coping" under their general coping construct. This complicates an inherently complex and interactive mediating process and assures that measures based on such concepts will generate analyses with confusing causal interpretations. Adoption of a behavioral definition avoids this confounding. The notion of "efforts to manage" as introduced by Lazarus and Folkman (1984) improves on other definitions in distinguishing coping and automatized adaptive behavior and reduces confounding with outcome with mastery. Modifying their definition accordingly, *coping is defined as specific acts or behavioral efforts on the part of family members to manage specific external and/or internal demands that are perceived as taxing or exceeding the resources of the person.* The model views coping as a consequence of perception in a manner consistent with Lazarus and Folkman (1984). This causal relationship is strengthened by the behavioral definition for coping.

| CAUSAL ANTECEDENTS | MEDIATORS | ADAPTATIONAL OUTCOMES |
|---|---|---|
| Caregiving Context | Perception | Family Impact |
| Internal Family Characteristics/Resources | Emotion | Social Functioning |
| Child Characteristics/ Resources | Coping | Morale (Life Satisfaction) |
| Primary Caregiver Characteristics/Resources | | Health |
| Available Formal Supports (Services) | | |
| Available Informal (Social) Supports | | |
| Other Community Characteristics/Resources | | |

Figure 6. Tentative Model for Family Caregiving

The relationship of emotion to the other mediating factors of coping and perception is more difficult to specify. *Emotion is used here to denote positive or negative feelings arising from a (cognitive and behavioral) response to a specific stressor.* This view is consistent with the more recent work of Folkman and Lazarus that views coping as a mediator of emotion and emotion as a product of both cognitive appraisal and coping effort. A major goal of the review that follows is to arrive at greater specificity with regard to the interrelationships of these three constructs. Despite what we consider to be conceptually distinct constructs, we remain concerned about the prospects of developing unique measures of each. We are particularly skeptical about separating emotion and perception. We are more optimistic about the likelihood of identifying or developing distinct measures for perceptions and coping given the behavioral definition provided for the latter. Measurement issues are a major focus of subsequent sections of this paper.

## ANTECEDENTS

A major function of the literature review in the following sections is to search for empirical evidence linking possible causal antecedents with process and outcome variables specified in the tentative model. The purpose here is to identify broad constructs that are identified in the two models applicable to a model of family caregiving for children with a disability or chronic illness. The Lazarus model is most helpful in its use of systems thinking in the identification of these processes. This perspective also highlights a major constraint of their work in that the *family* system is seldom considered. The focus on family is the major strength of the McCubbin and Patterson model which provides more specific ways of thinking about the population of interest here. In particular, research in this field provides more applications dealing with chronic problems affecting children, the impact of these children on other family members and the role of formal helping systems in this process.

The developing model of this paper applies a systems perspective to the "caregiving context" to identify six major domains from which antecedent variables might derive: (a) internal family characteristics/resources; (b) child characteristics/resources; (c) primary caregiver characteristics/ resources; (d) available formal supports (services); (e) available informal (social) supports; and (f) other community characteristics/resources (e.g., urban/rural, racial mix, average per capita income).

## ADAPTATIONAL OUTCOMES

The work of McCubbin and Patterson is perhaps weakest and most prone to circular thinking with respect to adaptational outcomes. Lazarus' model is more useful in its specification of three outcome domains: (a) social functioning; (b) morale (life satisfaction); and (c) physical health. Health is the most widely researched and most readily operationalized. In the context of family caregiving, of particular concern is the health of the primary caregiver and the child; however, health of other family members could be effected and should not be totally ignored.

Morale or life satisfaction is also more readily measured and relates to all family members. The complication here derives from the need to distinguish it from emotions arising immediately from the mediating process. This problem is exacerbated when the study methodology relies on retrospective self-reports of both the immediate emotion arising from a specific event or

circumstance related to the child's disability or illness and the overall life satisfaction of the primary caregiver or other family members. In this situation one would expect to observe a relationship between the reported emotions and life satisfaction outcome simply as an artifact of the data collection process. Lazarus' approach, employing longitudinal observation of events, is a logical methodological response. However, issues remain regarding the treatment of event data over time to arrive at summary measures which would be predictive of more general global outcomes like life satisfaction.

More troublesome is the measurement of social functioning. Actually any type of functioning (e.g. child, caregiver, family) seems to inherently blur cause and effect. Lazarus and Folkman acknowledge that "Social functioning over the long term is an extension of coping effectiveness in many specific encounters over the life course" (Lazarus & Folkman, 1984, p. 223). A major distinction appears to be around duration, with *social functioning referring to the long term fulfillment of various roles (e.g., parent, spouse, job-holder, or community member).* Coping, on the other hand, refers to behaviors associated with specific, more short term events. The distinction of coping as "efforts to manage" also separates mastery or positive outcomes more readily. However, in defining coping as "effort" rather than "mastery" the expected relationship with functioning, and possibly all outcomes, becomes unclear. Does the expenditure of more effort lead to positive outcomes? Clearly more coping effort could detract from the performance of other roles unless the coping is "successful." Would successful coping require less effort?

Such problems force Lazarus to search for ways to aggregate his event specific process measures of coping across events in an attempt to derive "styles of coping." These styles, which end up looking similar to the trait approaches that he criticizes, represent more stable measures that can be related to adaptational outcomes. This measurement issue is discussed in a subsequent section.

## CRITICAL MEDIATORS

In this section we look more closely at alternative conceptualizations of key mediating factors in our tentative caregiving model. Three major questions are addressed for each construct:

1. How is the construct defined at a conceptual level?

2. How has the construct been operationalized? and

3. What are the antecedents that have been linked to the construct?

This review is intended to subject the tentative model to a test leading to a reformulation of the model itself and/or a modification of the key constructs and definitions.

### PERCEPTIONS

Most of the literature on perception of the child's disability has been on children with developmental disabilities and chronic illnesses. No relevant literature could be found pertaining to the family's perception of children with serious emotional disorders. The concept of perception of the child's disorder has not been an exclusive area of study but rather it is studied in relation to families' coping with and adapting to, having a child with a disability.

In reviewing the literature there appear to be four primary conceptualizations of parents' perceptions of their child's disorder. The first of these constructs looks at how the parent/family define the disorder. The second construct has to do with the person's cognitive appraisal in a search for meaning of the disorder. The third construct has to do with the person's attribution of who is responsible for a "problem," as well as the level of responsibility or possibility of doing anything about it. The fourth construct looks at the cognitive adaptation of persons through the use of social comparisons. The following summary will look at each of these conceptualizations and some of the operationalized definitions in the research of parents' perceptions of their child's disability. While there is ambiguity and overlap in these conceptualizations we will attempt to highlight the differences and similarities in each major theoretical formulation. A review of the predictors associated with perception will also be offered.

#### Constructs

*Family definition of the event/stressor.* Hill's ABCX model highlighted two areas that had previously been overlooked -- the way families define events and their resources for coping with these events. The definition of the event, according to Hill, involves the individual values of the family's previous experience with stress which may range from seeing stresses as surmountable challenges to be met, to experiencing them as disastrous and uncontrollable. These factors, once introduced, seem to explain why different families presented with very similar threats or situations respond and fare so very differently (Hill 1949, 1958; Hansen & Hill, 1964).

In the expanded formulation of this model developed by McCubbin and Patterson (1982) two types of family perception are identified: (a) the family's perception of the event and the degree of stress they associate with it prior to the crisis; and (b) the family's perception of the crisis after it occurs. These perceptions interact with coping and together interact with new and existing resources available to the family. These together determine how the family adapts to the crisis.

In defining the T Double ABCX Model, McCubbin and McCubbin (1987) expand on Factor C to include appraisals at three levels. The first level is referred to as the family's appraisal of the specific stressor event, strain or transition. The second level is referred to as situational appraisals which include the family's subjective definitions of their demands, their capabilities and of these two factors relative to each other. The third level is referred to as global appraisals that make up the family schema for how it views the relationship of family members to each other and the relationship of the family to the larger community.

Even though the family's definition of the event (the "C" factor) is identified to be a critical family resource for coping and survival, there has been a lack of empirical research on this construct. In existing research, perception is frequently defined as a coping strategy and measured and analyzed accordingly. However, the theoretical framework provided by the ABCX model and its derivations do account for variations in family adaptation, and several studies seem to support this view (Abbott & Meredith, 1986; Anderson, 1981; Vonkrs, 1981). These variations are partly related to Factor C, which is conceptualized to include: (a) the subjective meaning the family gives to the stressor event itself; (b) the family's subjective definition or perception of their situation and the difficulties associated with it; (c) the family's perception of their resources and coping abilities, which might include the family's positive appraisal of the situation to make it more manageable or to maintain an optimistic outlook or acceptance; and (d) the family's beliefs or assumptions about themselves in relationship to each other, and their family in relationship to the community and the rest of the world. According to the T- Double ABCX Model, the stressor, family vulnerability, family typology, available resources, and family adaptive coping are all antecedents of and interact with the family's perception to determine how the family will adapt to the stressful event or transition.

Factor C appears to offer one structure for exploring the perception of families of children with chronic illness or disability and the role perception serves in facilitating family adaptation and accessing services. A number of studies have applied the ABCX framework to families who have children with developmental disabilities or chronic illnesses but none have focused on children with emotional problems. These studies have built on the theoretical formulations described and have expanded the body of knowledge regarding family's adaptation to stressful events. McDonald-Wickler (1986) utilized the ABCX Model as an organizing framework for her review of the literature related to family stress and mental retardation. She identified three studies that included perceptions as one of the variables studied. Behr (1989) looked at six other studies in her review that included perception as a factor. These studies are cited in the following sections as they relate to methods of measuring perceptions and to the identification of antecedent variables.

The work of McCubbin and others on the development of the T-Double ABCX Model provides us with a comprehensive and integrated theory and research base on family's adjustment and

adaptation to a stressor and/or strain. Their focus on the many interacting variables includes the family's perception of the stressor, their subsequent appraisal of the situation and their set of beliefs and assumptions.

*Cognitive Appraisal.* Another approach to perception looks at how individuals cognitively appraise what is happening to them and how they use this information to shape the course of events (Lazarus, 1983). This type of appraisal refers to the judgments people make about the demands and limits encountered in their interactions with the environment, as well as the resources for managing the demands. This process determines how people respond to the stressor or event, the feelings they experience, and how they adapt.

According to the theory there are three types of cognitive appraisal: primary, secondary and reappraisal. Primary appraisal is the way individuals evaluate how important an event is to their well-being. This is similar to McCubbin's definition of family appraisal of the event (McCubbin, 1987). Lazarus and Folkman (1984) call this type of appraisal "primary appraisal." They delineate three kinds of primary appraisal: irrelevant, benign-positive and stressful (Lazarus & Folkman, 1984). Irrelevant appraisals are judgments that an encounter with the environment has no implications for the person's well-being. Benign/positive appraisals occur if the outcome of an encounter with the environment is seen as positive, in that it enhances well-being or has the possibility to enhance well-being. Stress appraisals include: harm/loss, threat, and challenge. Harm/loss appraisals are judgments that some damage has already been sustained by the individual. Threat appraisals are when harms or losses have not yet taken place but are anticipated. Challenge appraisals focus on the potential for gain or growth inherent in an encounter.

For both threat and challenge the primary adaptational significance as distinguished from harm/loss is that they permit anticipatory coping. To the extent that the person can anticipate the future, individuals can plan for it and work through some of the difficulties in advance. Threat and challenge are not necessarily mutually exclusive. They can occur simultaneously and can shift as the encounter unfolds.

Secondary appraisal is more than an intellectual exercise in spotting all the things that might be done (Lazarus & Folkman, 1984). According to the theory it is a complex evaluative process that takes into account which coping options are available, which options have the likelihood of accomplishing what it is supposed to, and the person's ability to apply a particular strategy effectively. Secondary appraisals of coping options and primary appraisals of what is at stake interact with each other in shaping the degree of stress and the strength and quality of the emotional reaction. This interplay is usually very complex; it is similar to McCubbin's (1987) conceptualization of family situational appraisal which includes the family's subjective definitions of their demands, their capabilities and the interaction of these two.

Reappraisal, according to Lazarus and Folkman (1984) refers to a changed appraisal on the basis of new information from the environment, and/or information from the person's own reactions. It is simply an appraisal that follows an earlier appraisal in the same encounter and modifies it. In essence, appraisal and reappraisal do not differ.

According to this theory, appraisal can be influenced by person and situational factors. Situation characteristics that influence appraisal are: event uncertainty, temporal factors, ambiguity and timing. Event uncertainty incorporates the concept of probability in recognizing that the likelihood of an event's occurrence influences appraisal. Temporal factors that influence appraisal include imminence (how much time there is before an event occurs), duration, and temporal uncertainty (not knowing when an event is going to happen). Ambiguity is defined as the lack of situational clarity, different from uncertainty which is seen as a person's confusion about the meaning of the environmental configuration. The greater the ambiguity, the more person factors shape the appraisal. The fourth situational factor that can affect appraisal is the timing of the stressful event over the life cycle and in relation to other life events.

The identified person factors that are important determinants of appraisal include commitments and beliefs. A person's commitments and beliefs confer meaning on an event, and the situation factors selected have potential for creating threat. Situational and person factors can be considered antecedents of appraisal, but only in terms of their meaning with respect to the balance between demands and resources within the person, within the environment, and between the person and the environment.

The person's commitments and beliefs intermingle to shape the person component of the transaction. The nature of the event, its certainty, its temporal properties, its ambiguities and its timing all affect how the environment will enter into the transaction. Person and situation factors are always interdependent and their significance for stress and coping derives from the operation of cognitive processes that give weight to one in the context of the other.

Results from research applying this model support the role of appraisal in mediating stress and determining adaptational outcomes (Folkman & Lazarus, 1980; Lazarus, DeLongis, Folkman & Gruen, 1985; Frey, Breenberg & Fewell, 1989).

*Attribution of Responsibility.* Under attribution theory one could assume that parents' reactions to having a child with a disability are affected, in part, by their perceptions of the cause of the disability. (Brickman et al., 1975; Lasella & Keogh, 1980). That is, the nature and intensity of some parental affective reactions may be linked to their belief that they somehow caused the child's condition. Other parents, however, might believe that the disability was otherwise caused, i.e., that it was an accident, or an act of God. It is also reasonable to assume that parental response to the child and the disability will be affected by their view of the modifiability of the condition and by their self-perception of their ability to bring about change.

It may be that the concepts of parental locus of control, and feelings of responsibility for the child's condition, and internal or external perceptions of etiology and prognosis are useful in describing and explaining variability in parents' treatment and remediation decisions in regard to their child. One theory that lends itself to understanding the influence of attribution as it relates to perception is set forth by Brickman et al. (1982, 1983). He describes four helping models that differ in terms of the extent to which the help-seeker (in our case, parents) is held responsible for causing problems and whether or not the parent is held responsible for solving problems. Each model leads to a specific set of consequences regarding the help-seekers' perceptions about the agent responsible for observed changes (Bandura, 1977). In turn, the attributions of responsibility are likely to influence various health and well-being outcomes depending on the locus of the

attributions about causes, solutions, and change. While these models typically focus upon enhancing the helping process, conceptually these models also lend themselves to the purpose of investigating the parent's perception of their child's emotional disability.

Perception of the child's disorder, then, is determined by the parents' attribution of who or what is responsible for the problem plus their attribution of who or what is responsible for the solution. This leads to the recipient's locus of attribution about the agent responsible for observed changes which, in turn, according to the theory, influences well-being.

Brickman's models (1982) are moral, medical, enlightenment, and compensatory. In the moral model, help-seekers are seen as responsible for both creating and solving their problems. Individuals who see problems and needs from this perspective feel that others are not obligated to help, nor are they capable of helping. If help is offered, it is typically in the form of reminding persons that their fate is of their own doing. Brickman proposes that this perspective leads to loneliness, physical exhaustion, and other debilitating consequences because the burden of solving the problem rests entirely with the help seeker. The model does not sanction one to either request or accept help.

The second model is the medical model, in which the help-seekers are seen as responsible for neither the problem nor the solution. Under this model, individuals with problems see themselves and are seen by others as ill or incapacitated. They are expected to accept this state, which involves exempting them from their ordinary obligations and imposing on them the responsibility for seeking and using expert help. The advantage of this model for coping is that it allows people to claim and accept help without being blamed for their weakness. The deficiency of the model is that it fosters dependency which diminishes their ability to take control of their own problems and promotes a learned helplessness.

In the enlightment model, help-seekers are seen as responsible for their problems but are not viewed as capable of independently solving them. This puts the help-seeker in a dependent relationship in which he or she must submit to and follow regimens prescribed by "experts" in order to alleviate the problem. The model would appear to promote a sense of helplessness and dependency in terms of help-seekers' problem-solving abilities.

In the compensatory model, help-seekers are seen as the innocent victims of prior experiences and thus are not responsible for their problems. They are, however, held responsible for the solutions, within the model. Attention to the past is de-emphasized in this model and, consequently, the probability of increased guilt or attenuation or of self-esteem is reduced. This model emphasizes the client's acquisition of self-sustaining behaviors as well as fostering a sense of self-efficacy. The major consequences of this model include increased self-competence and well-being and the enhancement of adaptive coping abilities.

There is a body of direct and corroborative evidence regarding the helping models (Bandura, 1977; Karuza et al., 1982; Coates et al., 1983). In a study to establish the existence of the four helping models, Karuza found that each of the helping approaches could be differentiated in terms of attribution about causes for both problems and solutions (Karuza et al., 1982). In a study examining the extent to which adherence to certain helping models affected locus of attributions regarding the agent responsible for observed changes (Coates et al., 1983), findings supported the hypothesis that recipients who hold more strongly to models that reduce their responsibility for

solutions will be more likely to respond to help by becoming helpless. Other studies by Langer and Beneveneto (1978) not only found a greater display of learned helplessness type behaviors in situations where help-seekers were made to feel incompetent, but also found a greater degree of dependence on help-givers after help was provided to them.

While none of these studies looked expressly at the perception of a disorder, they support the contention that help-seekers' attributions about the causes and solutions to problems and attributions about the agent responsible for change do exist in at least the four models proposed. The link between the help-seekers perception of their responsibility for the problem and whether they are responsible for doing anything about it seems to influence behavioral outcomes that differentiate why people have varying capacities to both seek assistance or to utilize the help offered. This conceptualization also refines and enhances McCubbin's ABCX model in that it more clearly delineates the possible factors of the family's definition of the event and their subsequent appraisals that influence how they adapt. One of the problems with this conceptualization is that it looks at attribution of cause, solution and change in the context of developing enabling and empowering models of helping (Dunst & Trivette, 1987). The four models offered may only be points identified on a full range of perceptions that help-seekers (in our case parents) might possess. Also the conceptualization does not allow for help seekers to have a variety of attributions about causes and solutions or move through some process of change over time or based on the situation they are faced with. The model does not look at other factors that might influence the attribution of the problem or solution as McCubbin does, nor does it delineate the levels of appraisal that Lazarus and Folkman do in their conceptualization of adapting to stress.

*Cognitive Adaptation.* The fourth theoretical construct that provides a framework for understanding the role of perception in coping is cognitive adaptation (Taylor, 1983). The focus here is on the cognitive adaptations people may make when faced with a threatening event. Taylor (1983) proposes that adaptation to threatening events are mediated by 3 dimensions: a search for meaning of the event, increasing self-esteem, and establishing mastery over the event. Successful resolution of these cognitive themes depends on the individual's ability to form and maintain a set of illusions which requires that the person look at the known facts in a particular light (Taylor, 1983).

The theory suggests that people who encounter a threat or aversive experience search for meaning of two types. The first of these cognitions is to search for a causal analysis that addresses the question of why the event happened and what caused it. This is similar to Brickman's model of attribution of responsibility for the problem or need (Brickman, 1982) and McCubbin's "C-Factor", the definition of the event. The second cognitive search, according to Taylor (1983), is to look for the causal meaning which addresses the question of what meaning life has now. The person may initiate a search for the cause of that experience to establish or re-establish a sense of control or orderliness and predictability of the environment. There is support for the idea that identifying a cause is an important aspect of adaptation (Affleck et al. 1985). Whether the specific content of a causal attribution has a relationship to positive adjustment is not as clear. A person may blame a variety of sources for an event--oneself, others, the environment, God, fate or luck. These categories are similar to those proposed by Brickman.

The theme of enhancing self-esteem according to the theory of cognitive adaptation is served by six cognitive mechanisms. The first of these is downward social comparisons, in which the person makes a comparison between themselves and someone whom they perceive as less fortunate. The second cognitive mechanism is upward social comparisons, where the person makes a comparison between themselves and someone whom they perceive as doing slightly better. The third mechanism is focusing on attributes that make a person appear to be advantaged. The fourth mechanism is to create hypothetical worse worlds. The fifth mechanism is for the person to manufacture normative standards of adjustment that make the person's own adjustment appear positive. The final cognitive mechanism that serves enhancing self-esteem is construing positive benefits from the event (Taylor, Wood, & Lichtman, 1983).

Selectively evaluating oneself in ways that are self-enhancing is an internal resource used by individuals to limit their perceptions of themselves as a victim and limit their social perception as a victim in the minds of others. According to the theory it is through this process that people focus on the beneficial qualities of a given situation.

The theory suggests that mastery involves gaining a feeling of control over the aversive event so as to manage it or keep it from reoccurring (Taylor, 1983). The two types of control associated with this theme are direct and indirect control. Direct control is the belief that one can personally take active steps to control the course of events or prevent the event from happening. Indirect control is the belief that although one cannot personally control the event it can be controlled by others. A combination of both direct and indirect control is considered to be strongly associated with positive adaptation.

A number of studies have been conducted that support the relationship between the cognitive themes identified in the theory of cognitive adaptation and successful coping in response to various threatening events. These include: (a) accident victims (Bulman & Wortman, 1977); (b) victims of father-daughter incest (Silver et al. 1983); (c) victims of fire (Thompson, 1985); and (d) women with breast cancer (Taylor, et al. 1984). According to Behr's (1989) review of studies that are based on this conceptualization and incorporate the perspective of parents (rather then just the individual), the characteristics most frequently associated with perception include: (a) a reordering of priorities and a deeper appreciation of life; (b) an increased sensitivity to and compassion for others; (c) an appreciation for family and friends and a focus on closer family relationships; and (d) emotional growth (Thompson, 1985; Thompson, Bundek & Sobolew-Shubin, n.d.; Affleck, Tennen & Gersham, 1985; Affleck, et al. 1985).

Behr (1989) suggests that the Theory of Cognitive Adaptation provides an enhanced understanding of the cognitive processes associated with the C Factor (family perception) provided by the ABCX model. She further suggests that the theoretical framework of the ABCX model provides an enhanced understanding of the variables that influence cognitive processes associated with perception. She concludes that a comprehensive framework for research on perception should take into account both of these theories in addition to societal values, public policies and professional practices that also influence perceptions (Behr, 1989). We would add to this recommendation and suggest that the conceptualizations presented by Lazarus and Folkman (1984) and Brickman et al. (1982) also enhance the understanding of the perception factor of the ABCX Model and should be included in a more complex and comprehensive model that describes how families adapt to a child with a disability.

| Construct and Source | Definition |
|---|---|
| Factor C (Hill, 1949) | The person's definition of the event. |
| Factor C (McCubbin & Patterson, 1982; McCubbin & McCubbin, 1987) | Three levels: (1) Level 1 - family's appraisal of the specific stressor event, strain, or transition; (2) Level 2 - situational appraisals including the family's subjective definitions, of their demands, their capabilities and the interaction of demands and capabilities; and (3) global appraisals of the relationship of family members to each other and the relationship of the family to the larger community. |
| Cognitive Appraisal (Lazarus & Folkman, 1984) | Three types: (1) Primary appraisal - evaluation of how important an event is to the individual's well-being; (2) Secondary appraisal - evaluation of what can be done about the event; and (3) Reappraisal - changed appraisal resulting from new information from the environment and/or information from the person's own reactions. |
| Attribution of Responsibility (Brickman et al., 1983) | Helping models (moral, medical, enlightment, and compensatory) that differ in terms of the extent to which help-seekers are held responsible for causing and solving problems. |
| Cognitive Adaptation (Taylor, 1983) | Causal analysis that addresses the questions of why the event happened, what caused it and what meaning life has now. |

Figure 7. Alternative Conceptualizations of Perception

Lazarus' delineation of appraisal and Brickman's attribution of responsibility models give us a more through understanding of the family's definition of the stressor and the subsequent appraisals they make in dealing with a child with a disability.

**Measurement**

Attempts to define and measure family perceptions have been sparse. Reviews of stress and coping research tend to enumerate a series of coping factors without specifying them as resources or perceptions or both (McCubbin, et al. 1980). Studies of family perceptions of a child with a disability are even fewer. In a review of literature on families of a member with mental retardation based on the ABCX model, McDonald-Wikler (1986) identified only three studies that considered family perceptions as one of the variables. Behr (1989) selected six studies in her review that related to perception. The following is a summary of the major instruments utilized in these studies.

The Coping Health Inventory for Parents, (CHIP), (McCubbin, McCubbin, Nevin & Cauble, 1979) was developed to obtain self-reports of the parents' response to the management of family life when they have a child with a chronic illness. It appears to capture both coping behaviors and perceptions, however, the two are not conceptually distinguished by the designers. Instead, grouping of variables has been achieved by factor analysis. The instrument has been used in numerous studies (e.g., McCubbin, 1988; Flynt & Wood, 1989). The instrument is a 45 item self-reporting instrument to be completed by parents individually. The respondents indicate how helpful each coping behavior has been in managing the needs of their child. A four point rating scale is used, ranging from extremely helpful to not helpful. A principle components factor analysis with iterations identified three coping patterns that accounted for 71.1% of the variance of the original correlation matrix. The three patterns are as follows: (a) maintaining family integration, cooperation, and an optimistic definition of the situation; (b) maintaining social support, self-esteem and psychological stability; and (c) understanding the medical situation through communication with other parents and consultation with medical staff (McCubbin & Thompson, 1987, p. 177).

Cronbach's alpha computed for the items on each coping pattern showed reliabilities of 0.79, 0.79 and 0.71 respectively. Additional validity checks using the CHIP scales were made through a discriminant analysis between low and high conflict families of children with cerebral palsy. The results indicated that parents' use of all three patterns was significantly higher in the high conflict families which is consistent with the theory (McCubbin & Thompson, 1987).

Coping Pattern I, Maintaining Family Integration, Cooperation and an Optimistic Definition of the Situation, is of particular interest because of the items that appear to measure perception as defined here. The specific items that relate to perceptions and their factor loadings are: (a) believing that my child will get better (.68801), (b) believing that things will always work out (.67771), (c) believing in God (.61865), (d) believing that my child is getting the best medical care possible (.61175), and (e) believing that the medical center has my family's best interest in mind (.53492).

Another instrument developed by McCubbin, Larsen and Olson (1982) is called the Family Coherence Index (FCI). It is a part of the FIRA series of family measures, designed to assess the

critical dimensions and components of the T Double ABCX Model. The FCI consists of 4 items selected to record the degree to which families call upon their appraisal skills to manage stressful events. It is a self-report index asking the respondent to rate each statement on a 5 point scale from strongly disagree to strongly agree on 4 items. The items include: (a) accepting stressful events as a fact of life, (b) accepting that difficulties occur unexpectedly, (c) defining the family problem in a more positive way so they don't get discouraged, (d) having faith in God.

The psychometric properties of the FCI include a reliability index of .71 and a validity coefficient of .80 with the original FCOPES (McCubbin, 1987).

Working from the ABCX model, Abbott and Meredith (1986) developed the Family Adjustment Survey to assess the family's definition of its situation and coping resources. It consists of five open ended questions: (a) Is your family getting along as well as other families you know who do not have the extra challenges of raising a child with a disability?; (b) If so, how do or why are you coping successfully?; (c) Are there unique problems your family has faced because of your disabled child?; (d) Has your family developed any additional strengths as a result of this situation?; (e) What or who has given you the most help and support in dealing with the challenges of raising a child with a disability?

The responses to these questions were categorized and coded by two independent raters. The raters' 20 classification choices were treated as a comparison between two multinominal distributions. There was no significant disagreement between the coders at the .01 level of significance using a chi-square comparison test. No other psychometric properties of this rating procedure have been reported.

The Questionnaire on Resources and Stress-Friedrich (QRS-F) (Friedrich, Greenberg, & Crinic, 1983) is a shortened version of the QRS developed by Holroyd (1974) which also can be traced to the ABCX model. The QRS-F was developed using a three-step analytic procedure in which 52 items from the original 289 were identified as the most reliable. Factor analysis yielded four distinct factors: parent and family problems, pessimism, child characteristics and physical incapacitation. The correlation of scores between the QRS and the QRS-F was .997. Factor 1 is of particular interest. It is labeled Parent and Family Problems and consists of 20 items that assess the respondent's perception of the problems for themselves, other family members or the family as a whole. Items loading on this factor came exclusively from the QRS scales of Poor Health/Mood, Excess Time Demands, Lack of Family Integration, and Limits of Family Opportunity (Friedrich, Greenberg, & Crinic, 1983).

In addition to the administration of the QRS-F and other scales, Frey, Breenberg & Fewell (1989) utilized the Belief in Personal Control Scale (Schultz & Decker, 1985) and the Comparative Appraisals Scale developed for their study on stress and coping among parents of handicapped children.

The Belief in Personal Control Scale is a 5 item Likert scale used to measure perceived control over various life circumstances. The Comparison Appraisals Scale contains items composed from spontaneous comparisons made by parents in an another study that yielded 20 items that measure tendencies to make self-enhancing and self-depreciating comparisons. In order to control for systematic bi s they calculated Comparison Appraisal Scale scores as the proportion of ratings given for enhancing comparisons and the proportion of ratings for depreciating comparisons.

Dunst and Trivette (1987) have used an instrument developed by Gleason, Karuza, and Zevon (1981) that measures adherence to Brickman's four helping models. The Gleason instrument is a self-report instrument in which the items for each model are summed to determine the primary model to which the person adheres. Dunst reports dissatisfaction with this instrument and is in the process of developing another instrument that will measure adherence to the models (C. Dunst, personal communication, 1990).

Behr (1989) developed the Positive Contribution Survey to gather data for her study. The instrument is unique in its emphasis on the positive impact that children with disabilities can have on families. The instrument development was based on grounded theory that generated 16 categories of positive contributions that children with developmental disabilities make on their family. The data for the research was gathered from 267 parents of children with and without developmental disabilities. An exploratory factor analysis resulted in the identification of five factors labeled: (a) source of happiness and love, (b) source of family strength, (c) source of personal growth and maturity, (d) source of help and motivation, (e) source of knowledge about and compassion for special problems.

A summary of the various operational measures of perception is provided in Figure 8. For each measure, the theoretical orientation is indicated and a citation for the source or research employing the measure is provided.

## Antecedent Variables

A number of researchers have identified variables that contribute to or influence demands placed on families who have a child with a disability. Many of the factors identified are associated with perception. McDonald- Wickler (1986) and Behr (1989) each reviewed this literature and identified predictors associated with perception (Figure 9).

There are a number of studies identifying potential predictors of perception. Of these, some have identified the severity of the child's condition as a stressor variable that contributes to the demands placed upon the family (Friedrich, 1979; Wikler, 1986). Another child-related variable is age of the child (Gallagher, 1983). In a review of the literature, Byrne and Cunningham (1985) found that the age of the child and stages in the family life cycle are associated with stress of having a child with mental retardation.

A number of demographic variables have also been found to influence or be associated with stress in families with children who have a disability. These include socioeconomic status, (Gallagher, 1983), marital status (Beckman, 1983), and marital satisfaction (Freidrich, 1979).

Other predictive variables that have been associated with perception include the resources families use in dealing with stress. McCubbin et al. (1980) identified four resource categories: financial, psychological, social support and coping. Formal supports outside the family were found as the most important coping strategy in a study by Donovan (1988). Freidrich et al. (1985) found that marital satisfaction, maternal depression, loss of control and social support were important predictors of parental functioning. McKinney and Peterson (1987) found that support of the spouse and perceived control were significant predictors of family stress levels.

| Instrument/Source | Theoretical Orientation |
|---|---|
| Family Adjustment Survey (Abbot & Meridith, 1986) | ABCX Model |
| Questionnaire on Resources and Stress (Holyrod, 1974; Friedrich, Greenberg & Crinic, 1983) | ABCX Model |
| Coping Health Inventory for Parents (McCubbin, 1988) | ABCX Model |
| Positive Contribution Scale (Behr, 1989) | ABCX Model and Cognitive Adaptation |
| Stress Questionnaire (Folkman & Lazarus, 1988) | Cognitive Appraisal |
| Dunst and Trivette (1987) | Attribution of Responsibility |
| Belief in Personal Control Scale (Frey, et.al., 1989) | Cognitive Appraisal |
| Structured Interviews | |
| Anderson (1981) | ABCX Model |
| Vonkrs (1981) | ABCX Model |
| Glidden, Valliere, & Herbert (1988) | ABCX Model |

Figure 8. Selected Measures of Perception

Internal Family Characteristics/Resources

Life experience of family (McCubbin, 1979)
Life cycle of family (Byrne & Cunningham, 1985)
Socioeconomic Status (Dunlap & Hollinsworth, 1977; Farber, 1959; Gallagher et al., 1983)
World view/philosophy (Dunlap & Hollinsworth, 1977; Farber, 1959; Levinson, 1975)
Religious beliefs (Abbott & Meridith, 1986)
Spousal support (Abbot & Meridith, 1986; Freidrich et al., 1985; McKinney & Patterson, 1987)
Quality of marriage (Abbot & Meridith, 1986; Beckman, 1983; Freidrich, 1979)

Child Characteristics/Resources

Diagnosis/severity of disability (Pollner & Wikler, 1985; Wikler, 1986; Freidrich et al., 1985)
Age (Anderson, 1981; Farber, 1959; Gallagher et al., 1983)
Limitations (Barsch, 1964; Beckman, 1983)
Gender (Chigier, 1972; Farber, 1959)

Primary Caregiver Characteristics/Resources

Level of education (Dunlap & Hollinsworth, 1977; Farber, 1959; Levinson, 1975)
Social comparisons (Vonkrs, 1981)

Available Formal Supports (Services)

Resource availability (Abbott & Meridith, 1986)
Formal supports (Donovan, 1988)

Available Informal (Social) Supports

Social support (Freidrich et al., 1985)
Extended family support (McCubbin, 1988)

Other Community Characteristics/Resources

Community view of the child (Fairfield, 1983)

Figure 9. Summary of Causal Antecedents of Perception

## COPING

This section describes three major conceptualizations of coping found in the literature as an effort to discern what is meant by coping and how coping contributes to adaptational outcomes. The first views coping in the context of adaptive coping, the second in the context of cognitive appraisal, and the third in the context of cognitive adaptation. As was the case with the construct of perception, there is a fair amount of ambiguity and overlap in these conceptualizations of coping. In addition, there exists considerable overlap in the various definitions of coping and perception or appraisal. We will highlight the differences and similarities in each major formulation, review some of the measures of coping that have been utilized in research, and review the predictors associated with coping. It is important to remember that the concepts of coping and perception are not separate areas of study. Each must be studied in the context of individuals and families adapting to a stressful event. While clearly related and part of the same process, the intent here is to disentangle how coping and perception differ and the unique role of each.

### Constructs

*Adaptive Coping.* The origins for this conceptualization of coping are traced to the family stress research of Hill (1958), the ABCX Model. Hill identified the variables accounting for the family's vulnerability to a stressor event but failed to focus on the dynamics of coping and the family regenerative power. Subsequent research using Hill's ABCX Model, incorporated four additional factors found to influence the nature of family adaptation to crisis over time:

1. The pile up of additional stresses and strains;

2. Family efforts to marshal new resources from within the family and the community;

3. Resolution of the definition or meaning ascribed by the family to the event; and

4. Family coping strategies designed to promote adaptation.

These four factors were added to the original model and presented in the Double ABCX Model (McCubbin & Patterson, 1982). The Double ABCX model presents coping as a product of the interaction among the factors and as a predictor of the adaptability of the family to a stressful experience. It has proved to be useful in understanding the adaptation process of families confronted by a specific stressful event and the process of a family when confronted by an enduring stressful situation. The model acknowledges variability in internal and external coping resources, as well as acknowledging that the perception of the crisis event represents a powerful, though changeable, force in family's ability to cope. It also recognizes the importance of both internal and external resources to a family's vulnerability and regenerative power.

According to the Double ABCX model, a family may employ at least three basic adjustment strategies, used alone or in combination. These include: (a) **Avoidance**, defined as the family's efforts to deny or ignore the stressor and the demands in the hopes that they will go away or take care of them selves; (b) **Elimination**, defined as an active effort by the family to rid themselves

of the demands by changing or removing the stressor, or altering the definition of it; and (c) **Assimilation**, defined as the family efforts to accept the demands created by the stressor into its existing structure and patterns of interaction.

Factor B is the supply of resources available to the family. It influences the definition and appraisal of the demands on the family, and influences which coping strategies are used.

In an effort to further refine the Double ABCX Model, McCubbin and McCubbin (1987) developed the T- Double ABCX Model. Additional factors were incorporated into the model to include family types and expand on family strengths components (resources, coping and appraisal).

Of particular relevance to the discussion here is the PSC Factor--Problem solving and coping. The PSC factor is the family's management of the stressful situation through its problem solving and coping skills. Problem solving, according to the theory, refers to the ability of the family to define the stressor into manageable components, to identify alternative courses of action, to initiate steps to resolve issues and ultimately to solve the problem.

According to their formulation "coping refers to the family strategies, patterns and behaviors designed to maintain and or strengthen the organization and stability of the family unit, maintain the emotional stability and well being of family members, obtain and/or utilize family and community resources to manage the situation and initiate efforts to resolve the family hardships created by the stressor/transition" (McCubbin, 1987, p. 11). The family is viewed as a resource exchange network, and the action that facilitates the exchange is coping. They propose that specific coping behaviors can be grouped into patterns, such as coping directed at maintaining family integration. This particular pattern is one that has emerged from the research as important for families of children with chronic illness (McCubbin et al. 1983). Coping patterns are more generalized ways of responding that transcend various situations. They argue that it is more useful to view coping as a generalized response rather than situation specific.

The T- Double ABCX Model defines family coping as coordinated problem-solving behavior of the whole system, and complementary efforts of individual members which fit together as a synergistic whole. In their view the function of coping is to maintain or restore the balance of demands and resources. They define five ways the family system can maintain or restore this balance: (a) through direct action to reduce the number or intensity of the demands, (b) through direct action to acquire the additional resources not already available, (c) by maintaining existing resources so they can be allocated and reallocated as needed, (d) by managing the tensions associated with the ongoing stress, and (e) by using appraisal to change the meaning of a situation to make it more manageable.

In addition McCubbin and McCubbin (1987) define three system strategies that families often call upon to ease the strains of restructuring due to the pile up of demands and depleted resources over time. The three strategies are: (a) **Synergizing**, which refers to family efforts to coordinate and pull together as a unit to accomplish a shared lifestyle and orientation that can not be achieved by any single member alone; (b) **Interfacing**, which is referred to as the family working toward a better fit with the community due to the internal restructuring that has taken

place and therefore demand a new set of rules and transactions; and (c) **Compromising**, which is referred to as the strategy families use to achieve the community fit through a realistic appraisal of their circumstances and a willingness to accept a less than perfect resolution.

McCubbin and McCubbin's observations of family coping with transitions and non-normative life events outside of the family have revealed that the family strategies of coping are not created in a single instance nor directed at a single stressor. Because the family itself is a system the strategies involve the management of five various dimensions of family life at the same time. These dimensions include the following: (a) maintaining satisfactory internal conditions for communication and family reorganization, (b) promoting family members' independence and self esteem, (c) maintaining family bonds of coherence and unity, (d) maintaining and developing social supports in transactions in the community, and (e) maintaining efforts to control the impact of demands and the amount of change.

Coping then becomes a process of achieving the balance in the family between the individual member's growth and development and the family's organization and unity.

*Coping in the Context of Cognitive Appraisal.* A second conceptualization of coping that also refers to coping as a process is offered by Lazarus and Folkman (1984). Their review found two different theoretical literatures regarding the concept of coping. One of these is derived from traditional animal experimentation and the other from psychoanalytic ego-based psychology.

In the animal model, coping is frequently defined as acts that control aversive environmental conditions, thereby lowering psychophysiological disturbance. Lazarus and Folkman (1984) consider the animal model of coping simplistic and lacking in the cognitive emotional richness and complexity that is so much a part of human functioning. In the psychoanalytic ego-psychology model, coping is usually defined as realistic and flexible thoughts and acts that solve problems and thereby reduce stress. Behavior is not ignored in this model, but it is treated as less important than cognition. Also the psychoanalytic ego-psychological model differentiates between a number of processes that people use to handle person-environment relationships (i.e., Menninger, 1963; Hann, 1977).

The application of the psychoanalytic ego-psychological model often results in viewing coping structurally as a style or trait. According to Lazarus and Folkman (1984) this approach is inevitably incomplete and measures of coping traits or styles are not good predictors of actual coping processes, because they underestimate both the complexity and the variability of the ways people actually cope in specific stress situations.

In addition to the limitation of traditional approaches to understanding coping from a structural approach, Lazarus and Folkman (1984) identify other failings of both models. They emphasize the failure of the models to distinguish coping from automatized adaptative behavior. They see coping as implying effort rather than being automatized and underscore the need to differentiate between the two. An additional weakness of the traditional approaches is that coping is equated with adaptational outcomes. These conceptualizations do not allow for the investigation of the relationship between coping and outcome and they propose definitions of coping to include efforts to manage stressful demands, regardless of outcome.

The final failing of the traditional models of coping noted by Lazarus and Folkman is that these models equate coping with mastery over the environment. Lazarus and Folkman argue that many sources of stress cannot be mastered and coping processes that are used to tolerate such difficulties or to minimize, accept or ignore them are just as important as problem solving strategies that aim to master the environment.

Being careful to address the limitations and defects of the traditional approaches, Lazarus and Folkman (1984) define coping as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p. 141). This definition is seen as having several implications for the study of coping. First, observation and assessment should be concerned with what the person actually does. Second, what the person thinks or does (i.e., how they cope) should be examined in a specific context. Finally, the coping process means speaking of change in coping thoughts and acts as stressful events unfold.

They propose that the dynamics and changes that characterize coping are not random but rather they are a function of continuous appraisals and reappraisals of the shifting person environment relationship. They see coping as serving two functions. One function of coping is to manage or alter the problem with the environment causing distress, which is problem-focused coping. And the second function as regulating the emotional response to the problem, which is emotion-focused coping.

This theory suggests that the way a person copes is determined in part by the resources they have available. These include: health and energy; existential beliefs or general beliefs about control; commitments that hold a high motivational property that can help sustain coping; problem-solving skills; social support; and material resources. According to this conceptualization coping is also determined by constraints on the person and the environment. The personal constraints are internalized cultural values and beliefs about ways of behaving and psychological deficits. The environmental constraints that mitigate the use of resources include demands that compete for the same resources, and agencies or resources that thwart coping resources.

They argue that although it has been assumed that coping changes over the life course, the case has not been made empirically. They also are wary of stage formulations of coping as they imply an invariant sequence. Evidence suggests that there is substantial variance among persons in the ordering and duration of different kinds of coping across and within particular types of stressful events.

Matheny et al. (1986) offer an expansion of the conceptualization of Lazarus and Folkman (1984). In a review of the literature they find considerable interest in the study of stress and coping, however, researchers often leave terms undefined and assume that the reader already knows what is meant. The literature contains several different definitions of coping. For example Folkman and Lazarus (1980) define coping as including all cognitive and behavioral efforts to master, reduce, or tolerate demands. Others limit their definition to efforts to adhere to reality (Hann, 1977). Still others define coping as conscious efforts to deal with stressful demands (Stone & Neale, 1984).

While all of the authors reviewed agree that coping refers to the efforts to reduce stress, some give attention to psychodynamic processes while others limit their attention to the person's conscious efforts to deal with stress. Some of the studies reviewed include both healthy and unhealthy efforts to cope and others limited their focus on healthy coping methods. Matheny et al. (1986) define coping as "any effort, healthy or unhealthy, conscious or unconscious, to prevent, eliminate, or weaken stressors, or to tolerate their effects in the least hurtful way" (p. 509).

In an effort to organize the literature Matheny, et al., opt to limit the presentation to a taxonomy of categories of coping behaviors and coping resources identified in both the descriptive or theoretical literature. Their review yielded 17 distinct categories of coping plus an "other" category to subsume either behavior or resources cited in less than three studies.

As a result of the review and a meta analysis, an integrated model of stress coping is proposed. The stress model and the coping model are presented separately but the authors underscore the fact that it is integrative and comprehensive. Their model expands Lazarus' model to include both preventive and combative strategies of coping (Matheny, 1986). According to them there are four classes of preventive coping: (a) avoiding stress through life adjustments; (b) adjusting demand levels; (c) altering stress-inducing behavior patterns; and (d) developing coping patterns.

Five classes of combative coping strategies are identified: (a) monitoring stressors and symptoms; (b) marshaling ones' resources; (c) acting to eliminate or weaken stressors; (d) tolerating stressors one cannot eliminate; and (e) lowering stressful arousal.

McCubbin as well as Lazarus and Folkman emphasize the importance of process and the dynamic quality inherent in coping. They both discuss the notion of effort as being key in their formulations. McCubbin takes a behavioral focus of coping and defines strategies, patterns and behaviors that the family utilizes in adapting to a stressful event. Lazarus argues that this approach limits our understanding of coping and offers a definition that includes both cognitive and behavioral efforts that persons utilize to deal with stressful events. As a result they each define the purpose of coping differently. McCubbin defines the purpose of coping as to restore the balance between the demands and resources available, while Lazarus and Folkman see the purpose of coping as managing problems and regulating emotion. Folkman and Lazarus (1988) further view coping as a mediator of emotion and appraisal and offer a dynamic model in which coping arises during the encounter between appraisal and reappraisal and transforms the original appraisal and its attendant emotion in some way.
Both of the conceptualizations of coping work toward clarifying the ambiguity in previous understandings of coping in relation to stress. The work of Lazarus and Folkman appears to encompass the broadest understanding, but there is still a great deal of research needed before either of the formulations is fully supported. Integrating the two and drawing on their strengths would enhance this process.

*Coping in the Context of Cognitive Adaptation.* A third conceptualization of coping is based on the Cognitive Adaptation Theory for understanding victims' reactions to traumatic life experiences (Taylor, 1983). According to this model, many people hold a number of benign adaptive assumptions about the world and about themselves. These beliefs include the idea that the world is understandable and fair, that one's life is purposeful and meaningful, that there are reasons to be

hopeful and optimistic about the future and that one has control over important outcomes. A negative life event, such as a serious disease or injury can challenge these assumptions. Successful adjustment to these events depends upon maintaining or restoring a sense of meaningfulness, optimism and control. This approach shows some promise as a model for understanding and researching adjustment to negative life events or situations. There are a number of studies that support the theory that in adapting different types of victims find meaning in the event (Janoff-Bulman & Timko, 1987; Thompson, 1985), a sense of optimism (Antonoisky, 1979), and perceptions of control (Taylor et al., 1984; Thompson, 1981).

Coping with victimization includes coming to terms with shattered assumptions. The state of disequilibrium that results is marked by intense stress and anxiety. The coping process involves reestablishing a conceptual system that will allow the victim to once again function effectively. Thus the coping process will involve coming to terms with a world in which bad things can and do happen. The victim faces not only a reestablishment of a new world view but also the task of reestablishing a view of the world as meaningful, in which life events again make sense; and coping will involve regaining a positive self image, including self perceptions of worth, strength and autonomy (Janoff-Bulman & Frieze, 1983).

While this conceptualization is not as complex and integrative as McCubbin's or Lazarus' it does offer a perspective of the cognitive processes associated with coping, specifically as it relates to the reestablishment of self and the world.

**Measurement**

Theoretical frameworks for studying coping in families are markedly more plentiful than the measures available to operationalize those frameworks. The following summary will highlight some of the major instruments for measuring family coping.

The most extensive work on measures of family coping has been done by McCubbin and Patterson (1981). They have developed numerous instruments to assess coping strategies for families facing specific situations. These instruments include:

1. Families experiencing prolonged separation or divorce -- Family Coping Inventory;

2. Dual career families -- The Dual Employed Coping Scale;

3. Two parent families dealing with developmental and situational stressors -- The Family Crisis Oriented Personal Evaluation Scales;

4. Families caring for a chronically ill member -- The Coping Health Inventory for Parents (CHIPS); and

5. An adolescent family member coping with stress -- The Adolescent Coping Orientation for Program Experiences.

All of these measures are similar in scope, content, length and scoring procedures. Details of each measure and a discussion of validity and reliability issues can be found in McCubbin, 1987. A detailed description of one, the CHIPS, is in the section on perception.

Another instrument used to measure coping is The Folkman-Lazarus Ways of Coping Checklist (1986). This is a 66 item revised list spanning a range of thoughts and actions people use to deal with taxing events. This check list taps coping behaviors associated with ordinary stressful events in day to day lives. A factor analysis produced eight scales: confrontive coping; distancing; self control; seeking social support; accepting responsibility; escape avoidance; playful problem solving; and positive reappraisal. The checklist is binary and is always used with a specific event in mind. It is a process measure and when administered at regular intervals over time, can yield information on the consistency or variability in the individuals' coping mechanisms.

There are 27 problem-focused items and 41 emotion-focused items. Scores are derived from the summing of "yes" responses for each scale. The alpha coefficient of internal consistency of the problem focused scale is .80 and for the emotion focused scale is .81. The scales correlate at approximately .45.

Matheny and others (1986) produced an extensive taxonomy of factors frequently cited in the research as relating to successful stress coping. They developed a questionnaire called Coping Resources Inventory for Stress (CRIS). In 1986 it was undergoing its sixth revision and in that form it had 12 resource scales, two validity scales, three supplemental training scales, and an index of modifiability of scale scores.

Another instrument that has been developed to assess coping as well as the negative effects (strain) on families who have children with disabilities was the adapted version of the Impact on Family Scale (IFS) developed by Stein and Reissman (1980). McLinden-Mott and Braeger (1988) developed the Adapted IFS. The original IFS is a questionnaire that was developed for use with families of children with chronic illness. The authors adapted the questions to focus on disabling conditions. Parents rate each item on a scale of 4 (strongly agree) to 1 (strongly disagree). The original IFS contained 27 items reflective of impact on the family in general with an alpha of 86.

## Antecedents

Both McCubbin's and Lazarus' conceptualizations of coping identify the influence of resources in relation to coping. McCubbin and McCubbin (1987) identify three potential types of resources: personal, family and community. According to them the personal resources include innate intelligence, knowledge and skills, personality traits, physical and emotional health, a sense of mastery, and self-esteem. The family resources include cohesion, adaptability, family organization, shared parental leadership, clear family and generational boundaries, and communication skill. Community resources that are potentially available to families include all of the community-based resources such as medical and health care services, schools, churches, employers, etc. and government policies that enhance and support families. Of all of the resources in the community the one that has received the most attention in the stress literature is social support.

Lazarus and Folkman (1984) identified major categories of resources. They include resources that are primarily properties of the person, including physical health and energy, positive beliefs, and problem solving and social skills, and categories that are more environmental including social and material resources.

McDonald-Wikler (1986) reviewed the research on families of children with retardation and pinpointed several resources that could be classified as resources to the family. With these resources a family would be expected to cope more effectively with the stressor. The resources she identified include: social class, informal support networks, frequency of church contacts, as well as one's personal belief, social integration, and quality of the marriage.

While McCubbin and Lazarus incorporate the notion of resources into their models as mediators, it could be that the resources are antecedents to coping as they both talk about the resources as influencing the strategies people/families utilize to adapt to a stressful event. Based on their reviews and conceptualizations, one should consider all of the potential resources available and utilized to fully understand coping.

Because much of the research on adaptation to having a child with a disability does not differentiate between perception and coping, the antecedent variables identified in the previous section on perception are also applicable here. These include the following: the severity of the condition (Friedrich et al. 1985); age of the child (Gallagher, 1983); stage of the family life cycle (Byrne & Cunningham, 1985); socio-economic status (Gallagher, 1983), marital status (Beckman, 1983); marital satisfaction (Freidrich, 1979); support of spouse and perceived control (McKinney & Peterson, 1987).

## EMOTION

The tentative model posited in Section III identifies three mediators that act together to determine how a family will respond to the stress of having a child with a disability or chronic illness and the adaptive value of this response. That a stressful encounter would elicit certain thoughts, behaviors *and* emotions seems intuitively correct. Among many researchers and practitioners in the fields of mental health and behavioral medicine there is a long-standing and widely held conviction that the ways people cope with the demands of a stressful event influence how they feel emotionally (Folkman & Lazarus, 1988). However, emotion as a construct or measure, appears to be absent from the Hill and McCubbin models, including the most recent and highly elaborate T- Double ABCX Model. This absence may be in part explained by the sociological grounding of this line of work and its focus on family rather than individual processes. While concepts of "family stress" or "family behavior" challenge our thinking and measurement tools, addressing the question of "How the family feels?" is even more problematic.

On the other hand, the field of psychology, with its focus on the individual, has a produced a large body of theoretical and empirical literature on the topic of emotion. The early literature in this field treated emotion as a drive or motive and thus the causal antecedent to a cognitive and behavioral response. During the 1960's a newer conceptualization emerged in which emotion is viewed as flowing from cognition. Debate in the field today centers on the primacy of affect versus cognition. These different perspectives have implications for the conceptualization and

measurement of emotion and for the way one defines cognition, one of the other three mediating constructs. The two views are described in the following sections before turning to issues of measurement of emotion.

## Constructs

*Emotion as a Trigger.* Arguments for the primacy of emotion can be traced through the Middle Ages to classical Greece where the view was held that emotion or passion is primitive whereas thought and rationality were Godlike (Lazarus & Folkman, 1984). This perspective has been reinforced by evolutionary theories, and the study of emotion in animals and infants. If emotion precedes the development of cognition in the individual or species, then at that level of development no cognitive appraisal is necessary (or even possible) for the arousal of an emotional response (Zajonc, 1984; Isgard, 1984).

These evolutionary perspectives of emotion have been seriously challenged but not replaced by the more recent cognitive theories. Those currently arguing for the primacy of emotion maintain that affect and cognition are separate and at least partially independent systems thus permitting affect to be generated without a prior cognitive process and, at times, to precede cognition in a behavioral chain (Zajonc, 1984; Isgard, 1984; Tomkins, 1981; Plutckik, 1980). Tomkins (1981) argues that "Behaviorism, psychoanalysis, and cognitive theory each subjected affect to the status of dependent variable" (p. 306) and calls for an "affect revolution" to emancipate current thinking from "an overly imperialistic cognitive theory" (p. 306). In addition to the phylogenetic and ontogenetic evidence cited above, Zajonc (1984) cites the following evidence in support of this revolution: (a) separate neuroanatomical structures can be identified for affect and cognition, (b) appraisal and affect are often uncorrelated and separate, (c) new affective reactions can be established without an apparent participation of appraisal, and (d) affective states can be induced by noncognitive and nonperceptual procedures.

Those theorists arguing for the primacy of affect do not deny a role for cognition even as an antecedent to emotion under certain circumstances. Zajonc (1984) suggests the need for a line of research to determine under what conditions emotional arousal does not require cognitive appraisal and how these conditions differ from those that do (p. 122). These conditions do not appear to be well articulated in the literature. However, the evolutionary theorists seem to share, with others, a common belief in the existence of a subset of fundamental or basic emotions from which all others can be derived. While the argument is not clearly made, these basic emotions seem the most likely candidates to operate as direct triggers that do not require the intervention of cognitive appraisal. The lists of primary emotions posited by three such theorists (Tomkins, Isgard & Plutckik) are shown in Figure 10. The primary emotions identified by each author have been arranged to facilitate comparisons. Fairly close agreement among these authors can be seen to exist with six common emotions and only ten clearly unique motions identified across all three lists.

In Plutckik's model the eight basic emotions exist at maximum intensity. Lower levels of arousal exist for each ranging from the maximum primary emotion to a deep sleep at the bottom. Intermediate emotions are recognized and labeled at two levels. For example, grief is manifested at lower intensity levels of sadness and pensiveness; amazement as surprise and distraction. Other, more complex, emotions are hypothesized to arise from the mixing of primary emotions.

Numerous lists of such "emotion terms" can be found in the literature. These are described in more detail in the section on measurement. From the perspective of evolutionary theorists, it would appear that this "mixing" of primary emotions is more likely to involve cognitive appraisal.

The critical reader will note that while the above discussion provides a list of possible primary emotions and a process for "mixing" many more, no definition of the term has yet been provided. Such shortcomings are apparently common in this literature. A central tenet in Zajonc's (1980) critique of Lazarus work is that he has *defined* emotional reaction as requiring cognitive appraisal thereby making his proposition regarding the primacy of cognition impossible to falsify. On the other hand, Zajonc offers no alternative definition. In a much more comprehensive review of theories of emotion, Plutckik (1980) provides a list of 28 definitions of emotion found in psychological and psychiatric literature over the past 50 years. However, in reviewing these definitions he observes that there is little consistency or unanimity; no discernible trends over time; and many do not really qualify as definitions at all but "talk indirectly about some phenomenon (which we might label as X) without giving us any clear idea of what X is in familiar terms" (p. 83).

A common view, explicit in some definitions, is that there are three components or levels of manifestation of emotion: subjective affect, physiological changes, and action impulses and behaviors. The different theoretical orientations seem to differentiate their positions around the issue of what emotion is "not." Plutckik (1980), representing the evolutionary view, stresses that " . . . emotion is not to be considered as synonymous with a presumed inner-feeling state" and stresses the need to look for congruence of various classes of evidence (p. 103). Over 200 pages later he makes explicit what these other classes of evidence might be in the following definition:

> An emotion is an inferred complex sequence of reactions to a stimulus, and includes cognitive evaluations, subjective changes, autonomic and neural arousal, impulses to action, and behavior designed to have an effect upon the stimulus that initiated the complex sequence. These complex reaction sequences may suffer various vicissitudes, which affect the probability of appearance of each link in the chain. These complex reactions are adaptive in the struggle in which all organisms engage for survival. At higher phylogenetic levels, the patterns of expression associated with each chain of emotional reactions serve to signal motivation or intent from one member of a social group to another. Finally, there are eight basic reaction patterns that are systematically related to one another and that are the prototype sources for all the mixed emotions and other derivative states that may be observed in animals and humans.

The evolutionary theories cited in this section and the cognitive theories represented in the following section are not the only theories of emotion. Plutckik (1980) identifies four others including early behavioristic approaches and arousal theories, brain function theories, and psychoanalytic theories. These theoretical frameworks are not totally independent. Plutckik (1980) traces all theories to four major traditions in the study of emotions: evolutionary (Darwin), psychophysiological (James), neurological (Cannon) and dynamic (Freud). The debate over the primacy of affect or cognition is, however, a central issue in current conceptualizations of emotion and this debate is most evident in the opposing views of the evolutionary and cognitive theorists (see Lazarus, 1984; Zajonc, 1984). Brain function theories and research are frequently cited in support of the primacy of affect. Psychoanalytic theories (Brenner, 1975; Bowlby, 1968 as cited in Plutckik, 1980) generally acknowledge a mediating role for cognitive appraisal in transforming environmental events into emotional response.

| Tomkins | Isgard | Plutckik |
|---|---|---|
| interest | interest | adoration |
| surprise | surprise | amazement |
| joy | joy | ecstasy |
| anguish | distress | grief |
| fear | fear | terror |
| shame | shame | |
| disgust | disgust | loathing |
| rage | anger | rage |
| | contempt | |
| | | vigilance |

Figure 10. Primary Emotions (as cited in Plutckik, 1980)

In addition, the evolutionary and cognitive theories and particularly the more recent work of Lazarus are thought to be the most relevant to understanding the stress and coping process as it relates to families whose children have severe disabilities or chronic illness.

*Emotion as Part of the Coping Process.* Early cognitive views of emotion grew from a dissatisfaction with the principles of tension reduction as the basis of human and animal adaptation and learning (Lazarus and Folkman, 1984). Where evolutionary theorists stress that emotion is "not only" subjective feeling, cognitive theorists stress the limitations of physiological arousal, pointing out that autonomic arousal tends to be diffuse and generalized and that there is little evidence for distinct patterns of physiological arousal that correspond to specific emotions (Schachter & Singer, 1962). These early cognitive theories as exemplified by Schachter (1966) and Mandler (1975) viewed emotion as arising from a cognition-arousal interaction. Emotion is seen as a perception of arousal that is labeled according to available cognitive and environmental information.

Cognitive theories of emotion have been explored and advanced by numerous theorists and researchers over the past 25 years (see for example: Kemper, 1978; Weiner, Russel & Lerman, 1979; Beck, 1971, Ortony & Close, 1981; & Frijda, 1985). Lazarus and Folkman (1984) identify several commonalities in these theories:

> all share similar assumptions about the role of cognitive processes, especially evaluative ones such as cognitive appraisal, in the generation of an emotional reaction in an encounter with the environment. They are all meaning-centered, relational, process-centered, and recursive, that is, responsive at every stage to feedback and change (p. 269).

Of the cognitive theorists, the work of Lazarus and Folkman (1984, 1988) is viewed as the most relevant to our review because it is grounded in an attempt to understand the larger process of stress and coping. Lazarus has also been the main spokesperson for the primacy of cognition in debates with Zajonc. This battle of words seems to be, at least in part, a clash of personalities and philosophies that relies in part on a distortion of the other's position to fuel the debate. However, some important distinctions do exist.

Lazarus (1984) maintains that cognitive activity is a necessary precondition of emotion; that people must perceive that their well-being is implicated in a transaction before they can experience an emotion (p. 124). He also (and at the same time) argues that emotion and cognition cannot be separated. He is particularly critical of physiological arousal as a basis for defining emotion but stresses the need for meeting all three criteria, behavior, subjective reports and physiological changes, since each one can be generated by conditions that do not necessarily elicit emotion (p. 125).

Folkman and Lazarus (1985, 1988) identify two ways in which prior conceptualizations of emotion are incomplete. First they argue that the complexity, range and diversity of emotion is lost in these theoretical models. People are likely to experience multiple and often conflicting emotions even within a single stressful encounter. Second, they argue that these models

incorrectly suggest a unidirectional causal pattern in which emotion affects coping rather than recognizing the bi-directional relationship between emotion and coping in stressful encounters in which each affects the other.

Folkman and Lazarus are particularly critical of what they label reductionist thinking that characterizes the search for a limited number of primary emotions that underlie the large numbers of emotion words. However, they seem to incorrectly attribute this search to the assumption that "these dimensions adequately describe peoples' emotional states" (Lazarus & Folkman, 1984, p. 285). Such a conclusion does not seem to follow from Plutckik's theory of mixing of primary emotions and variations in their intensity levels. Knowing that blue and yellow can be mixed to yield green has not eliminated use of the color green to describe a tree.

While Lazarus (1975, 1984) does argue for the primacy of cognition in describing the *process* by which emotion is elicited he does not, as Zajonc (1984) describes, include cognition in his definition of emotion. Instead, Lazarus' definition is quite consistent with Plutckik and others who rely on the standard three response criteria:

> Emotion is a complex disturbance that includes three main components: subjective affect, physiological changes related to species-specific forms of mobilization for adaptive action, and action impulses having both instrumental and expressive qualities (Lazarus, 1975, p. 559).

In fact, Lazarus' argument for the primacy of cognition is not as uncompromising as he would have one believe judging from some of his statements. A truer statement of his position is that causality is bi-directional (Lazarus & Folkman, 1984). While at times he seems to suggest simultaneity, other statements and research based on the theory suggests a sequential process that can be made nonrecursive if the process is studied in sufficient detail and over sufficient time. Thus in the same publication, Lazarus and Folkman (1984) describe the relationship of emotion and cognition as dependent:

> ... on one's point of entry into the ongoing process. Thus, if the sequence seems to begin with (1) thought, followed by (2) emotion, followed again by (3) thought, and if we begin at point (1) in the above sequence, we must discover that cognition antecedes and in a sense probably determines emotion; however, if we start at point (2) in the sequence we must discover that emotion determines thought. Both principles, of course, are correct. (p. 274-275)

The real utility of the work of Lazarus and Folkman is not that they have a radically different or more accurate definition of emotion, but that they have looked at the role and place of emotion and cognitive appraisal in the context of the larger stress and coping process. This process is seen as beginning:

> with a transaction that is appraised as harmful, beneficial, threatening or challenging. The appraisal process generates emotion. The appraisal and its attendant emotions influence coping processes, which in turn change the person-environment relationship.

> The altered person-environment relationship is reappraised, and the reappraisal leads to a change in emotion quality and intensity. Viewed in this way coping is a mediator of the emotion response. (Folkman & Lazarus, 1988, p. 467)

Figure 11 presents a schematic diagram of this process in which coping acts as a mediator of emotion.

## Measurement

Emotions can be measured only indirectly through their manifestations at three levels: subjective reports of inner feelings, physiological changes and behaviors. Different theoretical orientations tend to be more preoccupied with measurement at only one or two levels. Thus evolutionary theorists tend to focus on physiological aspects of emotion and may focus even more narrowly on autonomic physiology or brain physiology. Cognitive theorists seem more comfortable working with subjective reports while psychoanalysts search the unconscious. Each of the levels of measurement is briefly described and examples of techniques or instruments provided in the following sections.

*Subjective Reports.* The measurement of emotions through introspective reports relies on the use of open-end questions and adjective checklists with the latter being the most common. These checklists present the subject with a series of mood or emotion words - such as calm, nervous, fearful or bored - from which the subject selects those describing their current or retrospective state. Most of the lists are atheoretical but responses are frequently subjected to analyses to determine underlying patterns and to reduce the larger lists to a small number of basic dimensions. Such analyses have not yielded conclusive results (Plutckik, 1980, p. 218) and have been highly criticized by some theorists (Lazarus & Folkman, 1984, p. 279). Nevertheless, Plutckik (1980) concludes that self-report checklists can be reasonably stable and can be valid indices of various life stresses or other conditions and thus serve as useful measures of emotion.

Numerous checklists have been developed and tested (see for example: Zukerman & Lubin, 1965; Nowlis & Nowlis, 1956; and McNair, Lorr, & Doppleman, 1971). One such checklist is the Mood Profile Index developed by Plutckik, Platman, and Fieve (1968) and consists of 36 pairs of emotion words such as annoyed, sad, amazed, greedy, and revolted. These terms were selected by a group of judges as representing the eight primary emotions at various levels of intensity. The pairing of emotions reflects the idea that all interpersonal personality traits can be conceptualized as resulting from the mixture of two or more primary emotions. Another checklist is one used by Folkman and Lazarus in their research and consists of 24 emotions which are scored separately. These two checklists also differ in their application. In responding to the Mood Profile Index, the subject is asked to describe their usual mood. Lazarus and Folkman use their checklist to obtain subjects' reports of feelings around a specific event at a specific point in time.

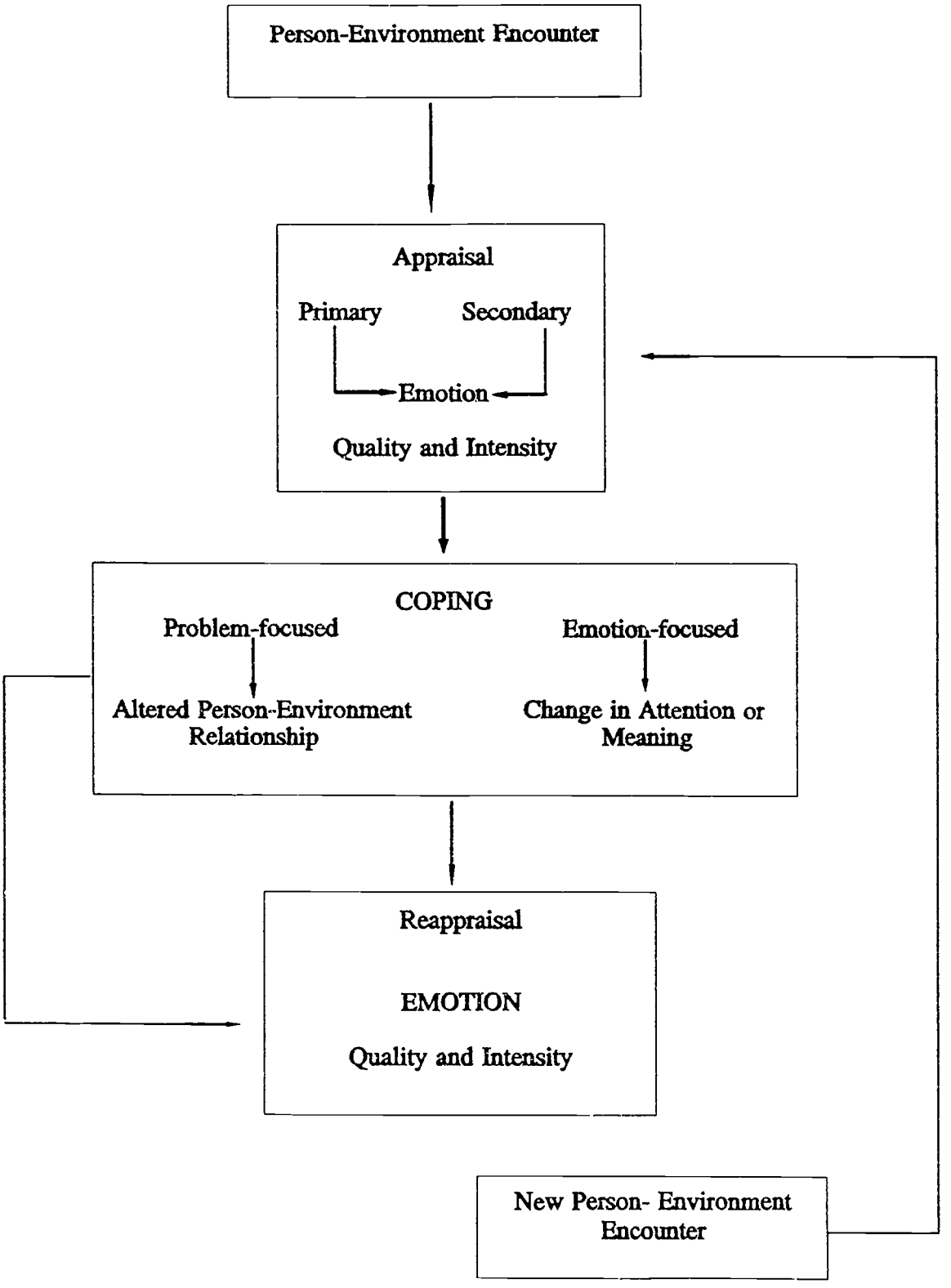


Figure 11. Coping as a Mediator of Emotion (Folkman & Lazarus, 1988)

*Physiological Measures.* There has been much interest in the measurement of autonomic changes as measures of emotion and this interest has spawned an immense body of research. This research has developed and utilized numerous kinds of physiological measures including electrical phenomena of the skin, blood pressure, electrocardiogram and heart rate, respiration rate, depth, and pattern, skin temperature, papillary response, salivary secretion, skin sweating, analysis of blood, saliva, and urine, gastrointestinal motility, metabolic rate, muscle tension, tremor and eye blink and eye movement (Young, 1961 as cited in Plutckik, 1980).

While physiological research, with its complex instruments and quantified measures, suggests a high level of sophistication, its utility for research on family caregiving is questionable at best. Most of this research has dealt with generalized stress or arousal rather than particular emotions. Numerous reviews of the literature on physiological measures have concluded that research results are so inconsistent that generalized conclusions cannot be drawn (see for example: Plutckik, 1980; and Strongman, 1978). Plutckik (1980) points to these additional problems with physiological measurement: disagreement regarding measurement techniques and procedures; independence of the modes of reaction of the different organ systems requiring multiple measures; the need for independent measures (self-report or behavioral observation); inability to differentiate mixed emotion states; and testing effects of the measurement procedures.

Even if these problems did not exist or could be overcome, the pragmatic problems involved with administering physiological tests for the study of stress and coping of individuals and families dealing with complex situations over extended time periods would severely limit their utility.

*Behavioral and Indirect Measures.* Behavioral measures are useful to study certain groups for whom self-reports of emotional states are not possible (e.g., severe mental disability, children and infants and animals) and to support or validate self-reports and/or physiological measures. Such scales usually require detailed observation by experienced judges. Interrater reliability is obviously important for behavioral rating scales. While some scales report high reliability coefficients, they tend to be scales developed to assess a limited range of emotions with a narrowly defined population, for example, anxiety in mental patients (see for example Hamilton, 1959; Plutckik, et al., 1970).

The study of facial expressions as displays of emotions has received considerable attention with mixed results. While it appears that facial expressions for some basic emotions such as rage, startle, fear and pleasure are universal and innate, they represent only one kind of display and can be learned and manipulated in humans (Plutckik, 1980, p. 284). This makes their use highly unreliable in assessing complex situational as opposed to event-specific emotions.

Closer to the context of family caregiving, Lazarus and Folkman (1984) provide what could be considered an indirect measure of emotion in their concept of "emotion-focused forms of coping." This term is used to denote "coping that is directed at regulating emotional response to the problem" (p. 150). Presumably, if one observed the coping behavior, one could infer that the emotion was present. For example, Lazarus and Folkman (1984) maintain that the more threatened the individual feels, "the more primitive, desperate, or regressive emotion-focused forms of coping tend to be . . . " (p. 168).

Using emotion-focused forms of coping to infer the presence of underlying emotions is problematic in the context of our attempt to understand the stress and coping process more fully and to explicate the separate components of this model in a way that leads to empirical testing. From this perspective, Lazarus and Folkman provide an interesting hypothesis to be tested rather than assuming the relationship to exist and exploiting it for measurement simplicity. The concept of "emotion-focused coping" may, in fact, hinder this endeavor by creating tautological definitions which assure the results of empirical tests. Lazarus and Folkman (1984) acknowledge this difficulty in their discussion of the difference between "cognitive reappraisal" and "emotion-focused coping," the latter of which can, it will be recalled, include "cognitive coping."

Other indirect measures of emotion include the Rorschach test, analyses of interview sessions for content and linguistic style, speech analysis and analysis of figure drawings (Plutckik, 1980). With the exception of the Rorschach which has been criticized as having low reliability and doubtful validity (Zubin, Eron, & Schumer, 1965), these methods appear to hold some promise (Plutckik, 1980). Their primary utility appears to be in assessing somewhat stable emotional states rather than event-specific fluctuations. As such, these measures may tap something closer to underlying personality traits rather than emotions tied to specific events or situations. However, distinguishing between personality traits and emotions represents a somewhat gray area in the emotion literature in any case. The major drawbacks to the use of these preferred indirect measures involves the complexity and costs of administering such tests. Recording methods can be complex and cumbersome. All require scoring by trained judges.

**Antecedents**

All theorists in this field agree that emotion arises from some external event in the environment that is "perceived" at some level by the individual. As noted above, differences exist regarding the level of cognitive activity required for the emotion to occur. Most theorists seem to agree that in most situations a cognitive appraisal occurs before the individual can experience the emotion. From this perspective, cognitive appraisal serves as a moderator variable or filter through which all sensory input is processed. It then seems to follow that the cognitive appraisal process is the only antecedent variable of consequence.

Are there environmental events that are translated directly into emotion? It will be recalled that this is the basic question underlying the debate between Lazarus (1984) and Zajonc (1984). No definitive answer can be given at this time, however, it seems that most scholars of emotion agree that the complex emotions evoked in the context of a parent providing care for a child with a disability or chronic illness are primarily the function of a prior cognitive appraisal. Support for this view, strongly advocated by cognitive theorists like Folkman and Lazarus, can be found in the writings of Plutckik, an evolutionary theorist. Plutckik (1980) notes that his definition for emotion (provided above)

> does not explicitly comment upon the nature of the stimuli that initiate the chain of reactions called an emotion. This is because the stimuli are too variable and subject to the accidents of conditioning history to be described in a general way. However, the *meaning*, or inferred cognitive evaluation, of a stimulus is crucial to the initiation of an emotional reaction (p. 361).

Some of the more elaborate models of the "emotion process" like those of Folkman and Lazarus (see above) and Frijda (1985) indicate that emotion arises initially out of an appraisal that the environmental event is of relevance to the individual. Lazarus refers to this as the primary appraisal. The emotional response (quality and intensity) is subsequently influenced and shaped by ongoing cognitive processes (secondary appraisal and reappraisal, in Lazarus' terms) and coping behaviors.

In conclusion, dominant theory suggests that emotion is primarily influenced by what have been identified here as the other mediating constructs of coping and cognitive appraisal.

## ADAPTATIONAL OUTCOMES

The impact of children with a disability on families is not well understood. Historically, detrimental effects on the family have been generally expected; however, there are apparently some families that do not experience those negative effects. It is important to understand the dynamics at work leading to successful adaptation. Stress and coping theory offer a possible model to explain the interaction of the numerous factors that may lead to various reactions to the disability. Unfortunately the most poorly defined component in the stress and coping models is the outcome. This section will identify the outcomes specified by the two theories that have been discussed extensively before, - ABCX Model (McCubbin & McCubbin, 1987) and Stress, Appraisal and Coping theory (Lazarus & Folkman, 1984). As both discuss the importance of the goal of adaptation or success, a summary of what constitutes successful family functioning within these and other theoretical frameworks is provided.

### BONADAPTATION OR MALADAPTATION

In the original conceptualization of the ABCX model, the X factor was labeled "crisis" or the degree of family disorganization (Hill, 1949). In more recent formulations, McCubbin and Patterson (1983) describe X as a series of reactions to the initial and subsequent events which, over time, lead to accelerating levels of bonadjustment --- growth and greater satisfaction -- or maladjustment --- dissolution and dissatisfaction. In the T Double ABCX, the model is expanded to include two related but discernible phases, termed the Adjustment phase and the Adaptation phase (McCubbin & Thompson, 1987).

According to this theory adjustment can be viewed as the short-term response by families, adequate to manage many family life changes, transitions and demands. Some stressful events do not create hardships for families. This depends on the family type, the resources they have available, coping and problem solving abilities, appraisals and vulnerabilities. However, in some situations, the hardships are numerous, severe, and demanding, and more significant changes result in the family system. According to the theory, when this happens the family will experience maladjustment and the resulting state of crisis (McCubbin, 1987).

Family crisis has been conceptualized as a continuous variable and is distinct from stress. Stress is defined as a demand capability imbalance resulting in and characterized by tension, and crisis is a state of family disorganization. Family crisis then is a transitional state in the family's effort to evolve and adapt to changes within and outside of the family unit. The movement of the family to initiate this change marks the beginning of the adaptation phase of the model. The process of the adaptation involves the integration and interaction of another set of demands, capabilities, resources, appraisals and coping strategies.

According to the theory, family adaptation simultaneously involves attentiveness and responsiveness to both the individual and the family level of functioning. A balance is sought between the two levels of interaction between the individual and family and the family and the community. Over time the family in crisis comes to realize that in order to restore some functional stability and/or improve family satisfaction they need to restructure, which may include modifications in established roles, rules, goals, and/or patterns of interaction. These processes

evolve over time as families work toward adaptation. Successful adaptation also requires coping efforts directed at system maintenance, including integration, morale, and member self-esteem (McCubbin, 1987).

The concept of adaptation is used to describe a continuum of outcomes to achieve the balance of functioning at the family member level and at the community level. The positive end of the continuum is called bonadaptation and is characterized by: (a) the maintenance and strengthening of family integrity; (b) a continued promotion of member development and family development; and (c) the maintenance of family independence and sense of control over environmental influence. Maladaptation--the negative end of the continuum--is characterized by an imbalance at either the family member level or the community level and is characterized by: (a) deterioration of family integrity; (b) curtailment of personal physical and/or psychological development; (c) a deterioration in the quality of the relationships at the subsystem level; and/or (d) the loss or decline of family independence and autonomy (McCubbin, 1983).

McCubbin and his colleagues have developed 7 indirect indices of family functioning, called the FIRA-G series. Two of these are intended to measure family adaptation, but only one is described in the literature. The Family Distress index is described as consisting of five items selected to record those difficulties families experience that may indicate deterioration in the family. The index includes family members with: (a) emotional problems; (b) the abuse of alcohol or drugs; (c) physical or psychological violence; (d) separation or divorce; and (e) deterioration in the marital relationship. This index was found to have a correlation of .50 with the original Family Inventory of Life Events (McCubbin & McCubbin, 1987). One can see that this operationalization of outcome is extremely limited and a great deal of further research is needed to more clearly delineate the components.

## APPRAISAL, COPING AND ADAPTATIONAL OUTCOMES

In the Lazarus and Folkman (1984) theory of stress appraisal and coping, three kinds of outcomes of the process of appraisal and coping are defined. These three basic outcomes are work and social living, morale or life satisfaction, and somatic health. Lazarus and Folkman further delineate that the outcomes are both short term and long term and note that there is not necessarily a one to one relationship between them. They too, like McCubbin, emphasize that they do not view stress as inherently maladaptative and deleterious. They acknowledge that some people can draw upon adaptive resources to an event and gain strength from the stress.

The first short term adaptational outcome according to this theory is conceptualized as social functioning. Social functioning is defined as the ways the individual fulfills his/her roles, as satisfaction with interpersonal relationships, or in terms of the skills necessary for maintaining the roles and relationships. According to this theory, social functioning is determined in part by the person's ability to manage effectively day-to-day events. Effectiveness of managing specific encounters depends on the match with the flow of events, the readiness of the person to react to certain types of situations as stressful (vulnerability), and the ability of the person to deal with the ambiguity of the encounter. Effective coping also depends on the match between the coping options and the actual coping demands and between the selected strategy and other personal agendas. Over the long term, social functioning is an extension of the specific encounters over the life span.

Morale is defined as how people feel about themselves and their conditions of life. In the short term, morale reflects appraisal about how well goals were achieved in dealing with specific events and how satisfied the person is with their performance. In the long run, morale depends on the person's appraisal of encounters as challenges and putting them in a positive light, as well as effective coping over a wide range of encounters.

The third outcome area according to Lazarus and Folkman (1984) is somatic health. This is the most widely researched outcome. It has long been assumed that illness is caused by stress, emotion, and coping. The controversy in the literature is whether there is generality or specificity in this relationship between stress and illness. Three possibilities through which coping can affect health are offered. These include: (a) the frequency, intensity, duration and patterning of neurochemical stress reactions; (b) using alcohol or drugs or carrying out activities that put the person at risk; and (c) impeding adaptive health/illness related behavior.

Lazarus and Folkman (1984) indicate that all three outcomes are interconnected and that good functioning in one does not mean the person is functioning well in all areas. They also report from their review of studies on all three outcomes that there are many methodological and empirical issues, that the focus of research is on general negative and positive outcomes, not on specific outcomes, that most of the data is self report, and that there are differences as to the definition of each outcome. As a result we are left with limited research to build on.

## SUCCESSFUL FAMILY FUNCTIONING

In both of the above models the emphasis on satisfaction or success is a critical component of adaptation. In her review of the literature on the ABCX model, McDonald-Wikler (1986) noted that we do not have a clear under standing of what is considered to be successful family functioning. In an effort to respond to this assertion, Summers (1987) looked at general family research and whether there were guidelines for measuring success in families. She looked at four broad theoretical orientations that were relevant to successful family functioning including: family systems theory, stress and coping theory, family life cycle theory, and social theories.

Within the family systems theories, Summers reviewed five models that provide some insights into the characteristics of successful families. The major idea derived from this review is that successful families maintain a balance between: (a) individuation and autonomy with mutuality and cohesion; (b) flexibility and problem solving with clear role expectations and clear boundaries; and (c) freedom of expression with supportiveness and affection. However, Summers cautions though that none of the models offers a clear-cut method for reliable identification of successful families that is independent of the life cycle.

One of the implications from the stress and coping theories for defining successful families is the concept of bonadaptation, which is closely linked to the concept of adaptability described in systems theory. The discussion of bonadaptation is related earlier as proposed in the work of McCubbin et al. (1983). Using this concept, a successful family is one that is capable of changing to meet the challenge of new situations and in the process of change reaches new levels of growth and development. A second implication of the theory for defining successful families is

the notion of demand-capability imbalance as a source of stress. According to the theory, a successful family would be one that is capable of meeting the demands of its members and the external community and is able to meet changing needs as they arise.

Several different conceptualizations of family needs and functions have been developed. Turnbull et al. (1984) categorize seven family functions: economic, physical care, socialization, recreation, affection, self-definition, and education. Cook (1986) suggests three categories of individual needs that families serve: personal growth and development, nurturance and support, and the provision of resources. Summers (1987) cautions that neither of these conceptualizations have been operationalized and tested but could serve as a basis for efforts to establish a taxonomy to measure family success.

According to the life cycle theories, successful families have two attributes: (a) the ability to accomplish successfully the tasks required at each developmental stage and (b) an ability to adapt to change. The latter according to Summers (1987) is similar to adaptability and bonadaptation as discussed earlier. Successful achievement of the developmental tasks requires the performance of specific roles at each stage. However, definitions and measures of successful performance of these roles are lacking.

In her review of the literature of the study of families within the context of culture, Summers (1987) looked at the issues related to marital quality and the values related to marriage and child raising styles in one or more cultures. She concludes that for marital quality there is a circularity between definitions of the outcome measure of marital quality and interpersonal factors. These factors include positive regard, emotional gratification, communications, role fit, and interaction. She suggests that these factors be considered for characteristics of a successful family. The values relevant to a successful family include egalitarianism, individualism and commitment, appropriate cultural child bearing practices, mutual encouragement of development and growth, as well as regard and respect.

Summers (1987) concludes that, while there are many factors that one could consider in defining what is meant by a successful family, her impression of the collective theories is a sense of incompletion. The variety of terms used to label the concepts leads her to suggest that they may not be sufficiently defined, nor clear, measurable or comprehensive. She concludes that what is needed is to compile a list of values and beliefs about family life against which families can measure their satisfaction.

As a first step in this process Summers conducted a qualitative study with open-ended interviews of 32 parents with and without children with disabilities. Nine major categories of values emerged: communication, flexibility, affection, responsibility, rules and roles, autonomy, closeness, support, and education (Summers 1987).

## FAMILY IMPACT

Another approach to outcome measurement attempts to assess the impact of chronic illness or disability on a family. Perhaps the best example of this approach is the Impact on Family Scale developed by Stein and Reissman (1980) to quantify the impact of childhood illness on a family and delineate the different facets of this effect. In developing this scale, the authors began with

an item pool of 190 items thought to represent four hypothesized dimensions which emerged from a literature review and interviews with a sample of mothers of children with a chronic illness. Consistent with the authors' conceptual framework, positive and negative impacts were considered in developing the list. The four hypothesized dimensions were: (a) economic burden, or the extent to which the illness changes the economic status of the family, drawing resources away from other areas; (b) social impact, or the quality and quantity of interaction with those outside the immediate household; (c) family impact, or interaction within the family unit including parental and sibling relationships; and (d) subjective distress, or the strain experienced by the primary caretaker that is directly related to the demands of the illness.

Judgments made by a panel of experts were used as criteria for selecting a sample of 58 items from the 190 to which empirical criteria could be applied. Analyses of pretest data on the 58 items were used to eliminate items that did not produce variability, were poorly worded and misunderstood by respondents or were highly redundant. A reduced list of 32 items was administered to a new sample. Eight additional items were eliminated as a result of low factor loadings or significant missing data. The authors describe the four generated factors as: (a) financial burden; (b) familial/social impact; (c) personal strain; and (d) mastery. Mastery contains five items that are independent of the other three dimensions and relates to coping strategies families use to master the stress of the illness.

In a subsequent study of families of children with developmental disabilities, McLinden-Mott (1988) utilized an adapted version of the IFS. Their findings indicated that the adapted IFS, when used with mothers of young children with disabilities, yields reliable and valid scores. In another adapted version, Stein and Riessman (1980) developed an instrument that can be used in studies of children with and without chronic illness. The psychometric analyses of this scale are not yet available but the scale might prove to be useful in measuring the impact of having a child with emotional problems without negative labeling of the child or their behavior.

The Impact-on-Family Scale appears to be a useful tool for assessing overall effects on families of having children with a chronic illness that can be readily adapted for use with families with children with various disabilities. However, it has two major drawbacks from the perspective of this review. The first involves the failure to differentiate mediators and outcomes in the stress and coping process as experienced by families. Thus many of the items on the scale are measures of coping strategies. In fact one entire factor is labeled "mastery." The second major drawback is that the scale is structured in such a way that families are directly asked to attribute the outcome to the child's illness. For example, the impact of the child's illness on family social functioning is assessed by asking the extent to which the mother agrees with the following statement, "We see family and friends less because of the illness." Our goal is to arrive at conceptually discrete measures and to empirically test relationships between these measures rather than ask the respondent's perception of the relationship.

## SUMMARY AND CONCLUSIONS

Most theory and research in the field of adaptation to stress has focused on the "coping process" rather than the outcomes of this process. Research on disability and the family, according to Knafl and Deatrick (1987), falls into two categories. The first assumes that having a family member with a disability is an inherently negative situation and that disruption of the family is an

inevitable consequence. Under the second category, research focuses on understanding the family's subjective definition of the situation and how the family manages the disability. The works of McCubbin et al. and Lazarus offer theories that separate outcomes from the coping process and attempt to more clearly explain the importance of various components of this process in determining adaptational outcomes. However, neither of these researchers have developed measures that fully delineate the concepts.

McCubbin's outcomes of adaptation and adjustment fall on a continuum from bonadaptation to maladjustment. However, bonadjustment/adaptation in this model tends to be defined tautologically as "successful coping." In addition the distinctions between adaptation and adjustment are not clear.

Lazarus and Folkman, on the other hand, offer a theoretical formulation of outcomes that includes three basic outcomes: social functioning, life satisfaction, and health. While they offer a more clearly delineated set of outcomes than McCubbin, most of their work on the operationalizing of the outcomes relates to only one of the outcomes, health (Folkman et al., 1986; DeLongis, 1988). While both of the theories talk about family well-being neither of them seem to have developed measures that relate to it.

Attempts to identify categories of family functioning (Summers, 1987; Turnbull et al., 1984) appear to hold promise. If these efforts are to succeed, they need to address problems arising from normative positions and value judgments that have arisen in attempts to define similar constructs like "social functioning" for individuals (Lazarus & Folkman, 1984, pp. 183-194). We are unaware of any existing tested instruments that operationalize "family functioning" as a construct distinct from coping behaviors and cognitive appraisals.

## REFORMULATED MODEL

The primary focus of this review is the process by which environmental events are mediated in forming the individual's and family's response that ultimately affects adaptational outcomes for family members and overall family functioning. With a sharper focus on the conceptual and operational definitions of the major identified mediators, the review has looked backwards in the stress process to identify causal antecedents and forward in an attempt to specify adaptational outcomes that capture desired end-states rather than the process leading to the end-state.

In conducting this review, we have encountered inconsistencies, limitations and numerous tautologies as well as insightful and creative theories, observations and research. Drawing from this work, we are now ready to rethink the original model providing greater detail and specificity. In the following section the newly formulated model is presented with a brief overview. Subsequent sections provide an expanded discussion of mediators, causal antecedents, and adaptional outcomes. The final two sections provide a closer look at operational measures for the overall stress process and for each of the major constructs identified in the model.

### MODEL OVERVIEW

The reformulated model is shown in Figure 12. The basic form of the model has remained the same with three major stages identified in the caregiving process: antecedents, mediators, and outcomes. The constructs under "causal antecedents" have changed the least. The primary contribution of the review to our understanding of this stage is the specification of specific causal antecedents that have been identified in the literature. These are summarized by conceptual grouping below in Section C. The mediating stage has been broken into additional components; however, all are included in the three original constructs of perception, emotion and coping. Adaptational outcomes have been expanded and focused. The three outcome areas identified by Lazarus and Folkman are applied to the primary caregiver in the family. One additional area, financial security, has been added. Constructs reflecting normalization of the child's life have been added to the model as adaptational outcomes.

The literature and research found to be the most relevant in building a model of family caregiving for children with a chronic illness or disability relate to the study of stress, coping and appraisal. If one follows the suggestion of Lazarus that stress be regarded as a rubric rather than a simple variable (Lazarus, 1966; Lazarus & Folkman, 1984; Lazarus, Delongis, Folkman & Gruen, 1985; Lazarus, 1990), the model of Figure 12 can also be thought of as a model of the "stress process." Indeed, family caregiving of children with a chronic illness or disability can be thought of as a special instance of stress and coping. While some of the unique characteristics of the family caregiving model result from simply applying more general stress models within this specific context, the model expands upon and differs in significant ways from previous conceptualizations.

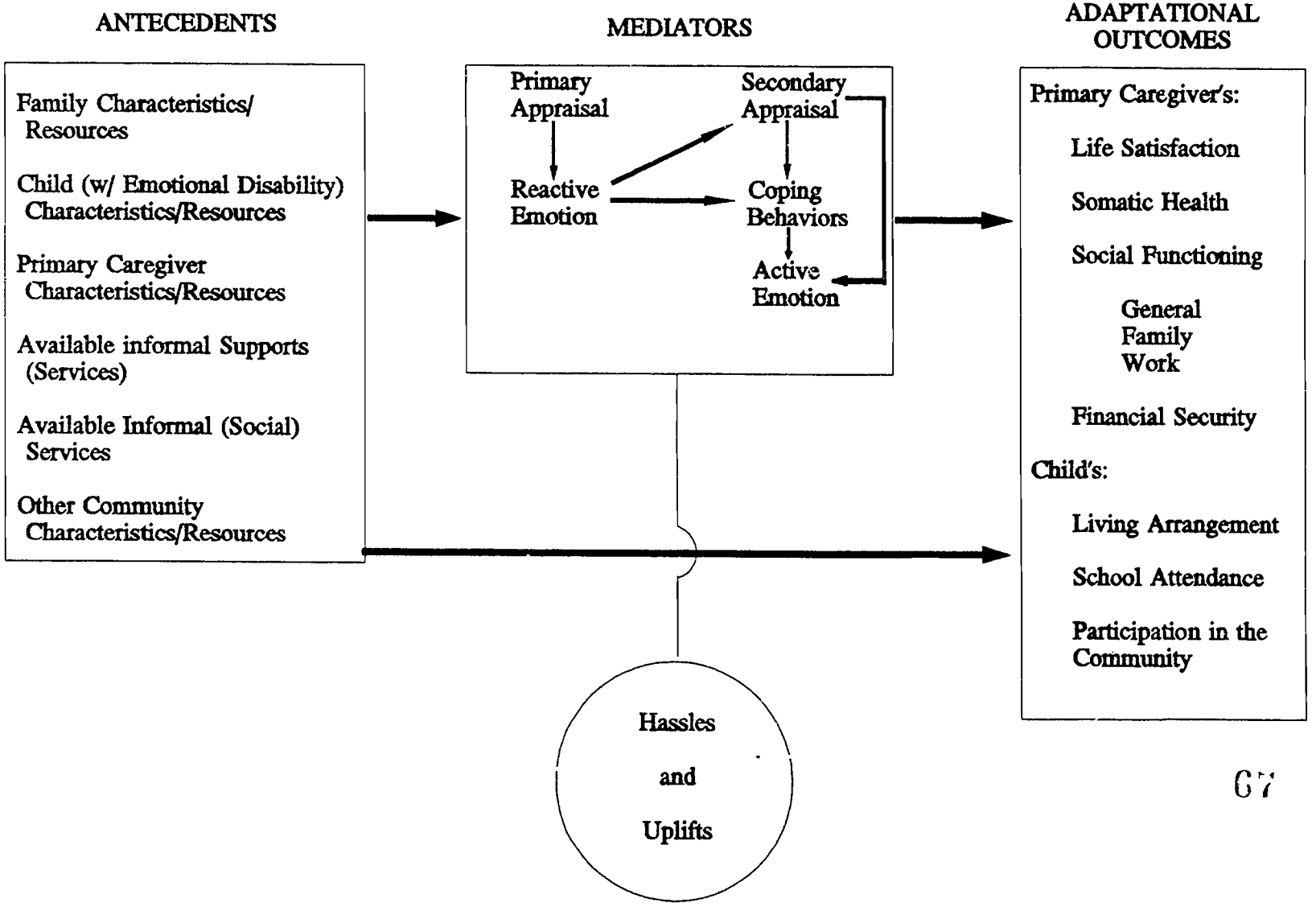


Figure 12. Family Caregiver Conceptual Model

## THE MEDIATING PROCESS

In the reformulated model, perception and emotion have each been split into two components. Coping retains the original definition with its focus on behaviors rather than cognitions. The hypothesized relationship between the resulting five constructs have also been specified in the reformulated model of Figure 12. The caregiving model draws heavily from the work of Folkman and Lazarus (1988) but also differs in significant ways.

The mediating process is seen as beginning with *primary appraisal*, which, utilizing the definition of Lazarus and Folkman (1984), is *defined as the judgment that an encounter or event is irrelevant, benign-positive, or stressful.* Emotion is seen as arising directly from this primary appraisal. We refer to this as *reactive emotion, defined as positive or negative feelings resulting from the perception of the stressor event.*

Also arising from the primary appraisal and influenced by the reactive emotion is the *secondary appraisal, defined as a judgment concerning what might and can be done and how the event or encounter should continue to be perceived.* The (primary and secondary) appraisal process and accompanying (reactive) emotion may then lead to a behavioral coping response. In some situations no behaviors will ensue. For example, the event may be judged to be irrelevant giving rise only to feelings of indifference with no further thoughts or actions; or the situation may be judged to be threatening but that nothing can be done to change it, giving rise to feelings of anxiety and vulnerability; or such an event could be reappraised with a decision to "try to ignore it."

The last example points to a major distinction of this model to that of Lazarus and Folkman in that reappraisal is not identified as a separate construct here. Conceptually, we find "reappraisal" troublesome as a distinct construct. In part the term is subsumed under "cognitive coping" strategies. We find it clearer to view coping as behaviors and cognitions as appraisals and thus include "cognitive coping" under secondary appraisal. We also find it difficult to distinguish reappraisal, particularly when it arises after coping efforts, as the final step of one encounter from primary appraisal in a second encounter. Doesn't the interaction of the person/environment modify the environment thereby initiating a new encounter?

As indicated in the above examples, secondary appraisal and the coping response give rise to a new set of emotions. In the caregiving model this is designated as *active emotion which relates to positive and negative feelings about the results of the appraisal and coping response.*

## CAUSAL ANTECEDENTS

One of the major junctions of the preceding literature review was to search for empirical evidence linking causal antecedents with process and outcomes identified in the tentative model of family caregiving. The six domains originally identified have been substantiated. A number of researchers have identified variables that contribute to or influence the demands placed on families who have a child with a disability. Most of the studies do not differentiate between those variables associated with perception or coping or emotion separately but rather identify those variables that influence the mediating process as a whole.

Family Characteristics and Resources
- Life experience
- Life cycle
- Socioeconomic status
- World view
- Quality of mental relationship
- Spousal support
- Religious beliefs

Child Characteristics
- Age
- Sex
- Severity of disability
- Child's limitations

Family Supports
- Formal (services)
- Informal (social)

Community Characteristics
- Size
- Racial mix
- Per capita income
- View of the child

Figure 13. Antecedent Variables Linked to Process or Outcome

The four major categories identified in the literature include: (a) internal family characteristics/resources; (b) child characteristics/resources; (c) family supports; and (d) community characteristics/resources. Following is a summary of the findings (Figure 13).

The internal family characteristics identified in the literature that affect the adaptational process include the life experience of the family (McCubbin, 1979); the life cycle of the family (Byrne & Cunningham, 1985); the socioeconomic status of the family (Dunlap & Hollinsworth, 1977; Farber, 1959; Flynt & Wood, 1989; Gallagher et al., 1983); and the family's world view (Dunlap & Hollinsworth, 1977; Farber, 1959; Levinson, 1975). Other research studies have identified the quality of the marital relationship (Abbott & Meredith, 1986; Beckman, 1983; Flynt & Wood, 1989; Freidrich et al., 1985) and spouse support (Abbott & Meredith, 1986; Freidrich et al., 1985; McKinney & Patterson, 1987) as variables that influence the mediating process of dealing with a child with a disability. The family's religious beliefs (Abbott & Meredith, 1986) have also been found to be a factor that influences how a family handles having a child with a disability.

According to the literature there seem to be four major child variables that influence the mediating process. These characteristics include the diagnosis or severity of the child's disability (Freidrich et al., 1985; Pollner & Wikler, 1985; Wikler, 1986); the age of the child (Anderson, 1981; Farber, 1959; Gallagher et al., 1983); the sex of the child (Chigier, 1972; Farber, 1959); and the child's limitations (Barsch, 1964; Farber, 1959).

Primary caregiver characteristics influencing the adaptational process include the level of education of the parents (Dunlap & Hollinsworth, 1977; Farber, 1959; Levinson, 1975) and whether they use social comparisons (Vonkrs, 1981).

The supports available to families seem to influence their capacity to deal with their child with a disability. Some studies have found that the availability of formal supports (services) influences the adaptational process (Abbott & Meridith, 1986; Donovan, 1988). Other studies have shown that the availability of informal (social) supports including the availability of the extended family (Freidrich et al., 1985; McCubbin, 1988) influences the family's capacity to deal with their child. The final category of variables that influence the mediating process is that of other community characteristics or resources. These include such variables as the size of the community, the racial mix of the community, the average per capita income, and the community view of the child (Fairfield, 1983).

## ADAPTATIONAL OUTCOMES

In assessing adaptational outcomes for families with children with chronic illness or disability, the conceptual framework provided by Lazarus and Folkman (1984) appears to be the most useful in that it more fully separates adaptational outcomes from the mediating process that determines these outcomes. It will be remembered, however, that this model focuses on stress, appraisal, and coping for individuals rather than for families. This is less problematic if the caregiving model explicitly focuses on individual family members, their personal situation and experience, and their experience of family functioning. Given the inherent problem involved in conceptualizing and operationalizing "family variables" that was discussed in a previous section, and the lack of agreed upon measures of family functioning, this is probably the best strategy to pursue at this time in any case.

While all family members should be considered as data sources in constructing an accurate picture of family impact, two members are of primary concern and should be viewed conceptually as the source for constructing outcome measures. In families with children with a disability or chronic illness it is unusual to find equally divided responsibility for caregiving. In most instances a primary caregiver, usually the mother, can be readily identified (Friesen, 1989). Also of central concern is the well-being of the child experiencing the disability or illness. By focusing on the adaptational outcomes of these two family members we have a better chance of building a consistent and valid model of family caregiving. Other family members are not to be ignored, but their activities and experiences are to be viewed from the perspective of their contribution to the functioning of the primary caregiver and the child living with a chronic illness or disability.

Lazarus and Folkman (1984) provide three conceptual categories for outcomes (social functioning, life satisfaction and somatic health) that can be readily operationalized and applied to the primary caregiver. To these we would add a construct reflecting the family's financial status. Unlike Stein and Reissman (1980) we would operationalize this construct as a distinct measure of financial stress and not attribute the burden to the child's illness or disability in the variable itself.

Operationalizing outcome measures for the child is more problematic. In the model being built, behaviors and certain aspects of the child's health are viewed as exogenous variables that influence both mediators and outcomes. One could expect the child's behaviors or health at an earlier point in time to influence the family's appraisals, emotions and coping behaviors and, ultimately, current and future behavior and health. With adequate prospective longitudinal studies, such models could be estimated. Cross-sectional or retrospective studies will find it harder to disentangle these effects.

Another important set of adaptational outcomes for the child lend themselves more readily to study. These outcomes reflect the recent emphasis of federal law (PL 94-142 and PL 96-272) on normalizing living arrangements. Positive adaptational outcomes here would be reflected in the ability of the family to keep the child in their home or minimize placement days when placement was necessary, the child's ability to attend and participate meaningfully in school, and participation in other community activities appropriate to a child of this age.

### Hassles and Uplifts as Indicators

Lazarus and his colleagues have developed the idea of "hassles" as important in the process of responding to stress. The discussion here focuses on the possible use of the instrument developed by Lazarus and his colleagues (Kanner et al., 1981; DeLongis et al., 1982; Lazarus & DeLongis, 1983; Lazarus & Folkman, 1984; Lazarus, 1990) measuring "hassles of daily living" as an overall indicator of the mediating process.

"Hassles" is a term use to describe the "irritating, frustrating, distressing demands and troubled relationships that plague us day in and day out" (Lazarus & DeLongis, 1983, p. 247). Examples of hassles are concerns about news events, traffic, yardwork, cooking and eating at home, and car maintenance. Subsequent revisions of this scale produced the *Hassles and Uplifts Scale* which consists of 53 items identifying sources of every day stress.

The placement of "hassles" in the overall model of Lazarus and Folkman (1984) is unclear. Diagrams of their model do not include the term "hassles." In the first article to report the use of the scale (Kanner, Coyne, Schaefer, & Lazarus, 1981), it is portrayed as an independent variable and is contrasted with a scale of larger life events as a measure of "stressors," which would seem to imply its use as a causal antecedent. Subsequent articles have also pitted hassles against life events (Lazarus & Folkman, 1984; Dohrenwend & Shrout, 1985; Lazarus, DeLongis, Folkman & Gruen, 1985). In their book, Lazarus and Folkman (1984) discuss hassles as a measure of "stress," a term which the authors generally use to indicate an overall process rather than a specific input, response or outcome. However, this discussion occurs in a section describing measures of "variables" which are listed to include "stress." Dohrenwend and Shrout (1985) suggest that it is more a dependent variable or outcome measure. They point out that, consistent with this view, Lazarus and his colleagues advocate as an important next step the investigation of personal and environmental antecedents of individual and group differences in hassles experience.

It appears that the original hassles checklist was designed as a measure of the overall stress process and thus included items that reflected external conditions, coping and appraisal activity as well as adaptional outcomes or indicators of outcome states. However, such a scale does little to forward the line of research pursued by Lazarus and his colleagues particularly in their attempt to explicate a causal process. While taking defensive positions in debates with Dohrenwend and their colleagues, Lazarus has retreated somewhat in revising the scales to exclude some items that were shown by Dohrenwend et al. (1984) to be most highly correlated with symptoms of psychological adaptation.

In our view the issue of confounding and whether hassles represents an independent or dependent variable can be readily solved conceptually but will require some modification of the scales at an operational level. Hassles and Uplifts do not represent some independent, objective environmental input that is comparable to a life event list. As Lazarus has emphasized, hassles and uplifts clearly incorporate appraisal and cannot be separated from it (Lazarus, DeLongis, Folkman & Gruen, 1985). However, the individual's experience of hassles and uplifts also incorporates attempts to deal with daily demands and their resulting feelings. Hassles and uplifts are a measure of how someone *feels* about their *coping* efforts to respond to a *perceived* demand. Hassles and uplifts provide a rich description of the mediating process. As such, they represent both a dependent variable with personal and environmental causal antecedents that can be identified and tested and an independent variable that can legitimately be considered in attempts to explain adaptational outcomes.

To apply the Hassles and Uplifts Scales in this manner will require closer scrutiny of scale items and research of the type carried out by Dohrenwend et al. (1984). Hassles and uplifts can be most useful if the items focus on activities of daily living such as eating at home, preparing meals, getting ready to leave the home and caring for pets. With such a scale one can then empirically determine what in the environment (e.g. social supports or formal services) or what about a child's behavior or condition causes the performance of these activities of daily living to be experienced as positive or negative and whether and how this experience of a hassle or uplift impacts adaptational outcomes.

MEASUREMENT

One of the major tasks of the review was to identify existing instruments that measure constructs of the family caregiver model. A number of instruments have been developed to assess aspects of the process, but none have been successful in looking at the process as a whole. Many of the instruments look at individual measures of stress at a single point in time (Friedrich, Greenberg, & Crinic, 1983; Holyrod, 1974; Lazarus & Folkman, 1987; Matheny et al., 1986), while others attempt to measure stress at the family level (best exemplified by the work of McCubbin et al. cited in McCubbin & Thompson, 1987).

In the formulation of the Family Caregiver Model three major stages have been identified in the process of family response to the demands of caring for a child with a disability. The three stages in the model are identified as antecedents, mediators and outcomes and are consistent with both the Lazarus and McCubbin models.

Measures of the antecedent variables that have been found to influence the mediating process are easiest to select based on the literature as summarized in section "C." These variables include the sex of the child, the age of the child, the relationship to the child, the parents' employment status, the income of the family, the marital status of the parents, the parents' education, the race of the family, and the religious beliefs of the family. Other antecedent variables that need to be assessed include characteristics of the child's disability, the availability and use of formal and informal supports, and information about the community in which the family resides.

It is not as easy to find instruments that measure the mediating process as we have defined it. Most measures have not separated out the outcomes from the mediators or don't even measure outcomes; as a result, it is difficult to select instruments that assess the critical process of perception, coping and emotion. This is also the case with trying to locate instruments that assess the adaptational outcomes as we have defined them. The following summary table (Figure 14) presents the constructs, a description of the measure that best assesses the construct based on our review, and the primary author of the instrument.

The formulated model synthesizes the two dominant existing models. The new model identifies outcomes for children with a disability and for the primary caregiver of that child. The new model identifies the mediators that are thought to contribute to these outcomes, viewing the mediating process as a complex interaction of appraisal, emotion and coping behaviors. The model draws on previous research to identify antecedents of the mediating process as well as the outcome. Finally, the new model considers the developing concept of hassles and uplifts from Lazarus and Folkman and its potential relationship to the mediating process.

| CONSTRUCT | INSTRUMENT | AUTHOR |
|---|---|---|
| ANTECEDENT VARIABLES | | |
| Sex of Child | | |
| Age of Child | | |
| Parents' Employment | | |
| Marital Status | | |
| Parent Education | | |
| Race | | |
| Income | | |
| Religious | | |
| Severity of Disability | Child Behavior Checklist | Achenbach (1981) |
| Family Supports | Family Coping Coherence Scale | McCubbin & Patterson (1981) |
| Social Supports | Social Support Index Stress Questionnaire | Folkman & Lazarus (1985) |
| MEDIATORS | | |
| Perception | Positive Contribution Scale | Behr (1989) |
| | Coping Health Inventory for Parents | McCubbin et al. (1983) |
| Coping | Coping Health Inventory for Parents | McCubbin et al. (1983) |
| | Stress Questionnaire | Folkman & Lazarus (1985) |
| Emotion | Stress Questionnaire | Folkman & Lazarus (1985) |
| ADAPTATIONAL OUTCOMES | | |
| Life Satisfaction | Preventive Measures | Press (1986-1989) |
| Somatic Health | | |
| Social Functioning | | |
| Child's Living Arrangement | Child Behavior Checklist | Achenbach (1981) |
| School Attendance | | |
| Participation in Community | | |

Figure 14. Model Constructs and Data Sources

## REFERENCES


Abbott, D.A., & Meredith, W.H. (1986). Strengths of parents with retarded children. *Family Relations, 35*, 371-375.

Affleck, G., Tennen, H., & Gershman, K. (1985). Cognitive adaptations to high-risk infants: The search for mastery, meaning and protection from future harm. *American Journal of Mental Deficiency, 89*(6), 653-656.

Anderson, J. (1981). The social construction of illness experience: Families with a chronically-ill child. *Journal of Advanced Nursing, 6*, 427-434.

Antonoisky, A. (1979) *Health Stress & Coping*. San Francisco: Jossey-Bass.

Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review, 84*, 191-215.

Barsch, R.H. (1964). The handicapped ranking scale among parents of handicapped children. *American Journal of Public Health, 54*, 1560-1567.

Beck, A. (1971). Cognition, affect and psychopathology. *Archives of General Psychiatry, 24*, 490-500.

Beckman, P. (1983). Characteristics of handicapped infants: A study of the relationship between characteristics and stresses as reported by mothers. *American Journal of Mental Deficiency, 88*, 150-156.

Behr, S. (1989). *Underlying dimensions of the construct of positive contributions that individuals with developmental disabilities make to their families: A factor analytic study*. Unpublished doctoral dissertation, The University of Kansas, Lawrence, KS.

Bowlby, J. (1969). *Attachment and loss: Volume 1, Attachment*. New York: Basic Books.

Brenner, C. (1975). Affects and psychic conflict. *Psychoanalytic Quarterly, 44*, 5-28.

Brickman, P., et al. (1975). Cause chains: Attribution of responsibility as a function of immediate and prior causes. *Journal of Personality and Social Psychology, 32*(6), 1060-1067.

Brickman, P., et al. (1982). Models of helping and coping. *American Psychologist, 37*, 368-384.

Brickman, P., et al. (1983). The dilemmas of helping: Making aid fair and effective. In J. D. Fisher, A. Nadler and B.M. Depauls (Eds.), *New Directions in helping: Vol. 1. Recipient reaction to aid*, 18-51. New York: Academic Press.

Bulman, R.J., & Wortman, C.B. (1977). Attributions of blame and coping in the "real world": Severe accident victims react to their lot. *Journal of Personality and Social Psychology, 35*(5) 351-363.

Burr, W.R. (1973). *Theory construction and the sociology of the family*. New York: John Wiley & Sons.

Byrne, E.A., & Cunningham, C.C. (1985). The effects of mentally handicapped children on families: A conceptual review. *Child Psychology and Psychiatry, 26*(6), 847-864.

Chigier, E. (1972). *Down's Syndrome*. Lexington, MA: D.C. Heath.

Coates, D. et al. (1983). When helping backfires: Help and helplessness. In J. D. Fischer et al. (Ed.), *New directions in helping: Vol. 1. Recipient reaction to aid*, (pp. 251-279). New York: Academic Press.

Cook, D. (1986). *Assessing the impact of self-help intervention for army soldiers who have developmentally disabled family members*. Unpublished doctoral dissertation, The University of Kansas, Lawrence, KS.

Coyne, J.C., & Lazarus, R.S. (1980). Cognitive style, stress perception and coping. In I.L. Kutash, L.B. Schlesinger & Associates (Eds.), *Handbook on stress and anxiety* (pp. 144-158). San Francisco: Jossey-Bass.

Crinic, K.A., Friedrich, W. & Greenberg, M. (1983). Adaptations of families with mentally retarded children: A model of stress, coping and family ecology. *American Journal of Mental Deficiency, 88*(2), 125-138.

Delongis, A., et al. (1982). Relationship of daily hassles, uplifts and major life events to health status. *Health Psychology, 1*, 119-136.

Delongis, A., Folkman, S., & Lazarus, R. (1988). The impact of daily stress on health and mood: Psychological and social resources as mediators. *Journal of Personality and Social Psychology, 54*(3), 486-495.

Dohrenwend, B., et al. (1984). Symptoms, hassles social supports and life events: The problem of confounded measures. *Journal of Abnormal Psychology, 93*, 222-230.

Dohrenwend, B., & Srout, P. (1985). Hassles in the conceptualization and measurement of life stress variables. *American Psychologist, 40*, 780-785.

Donavan, A.M. (1988). Family stress and ways of coping with adolescents who have handicaps: Maternal perceptions. *American Journal on Mental Retardation, 92*(6), 502-509.

Dunlap, W.R., & Hollinsworth, J.S. (1977). How does a handicapped child affect the family? Implications for practitioners. *The Family Coordinator, 26*(3), 286-293.

Dunst, C., & Trivette, C. (1987). Families: Conceptual and intervention issues. *School Psychological Review, 16*(4), 440-456.

Fairfield, B. (1983). Parents coping with genetically handicapped children: Use of early recollections. *Exceptional Children, 49* (5), 411-415.

Farber, B. (1959). Effects of severely mentally retarded child on family integration. *Monographs of the Society for Research in Child Development.* (Serial No. 71).

Flynt, S., Wood, T. (1989). Stress and coping of mothers of children with moderate mental retardation. *American Journal on Mental Retardation, 94,*(3), 278-283.

Folkman, S., et al. (1986). The dynamics of a stressful encounter: Cognitive appraisal coping and encounter outcomes. *Journal of Personality and Social Psychology, 50*, 992-1003.

Folkman, S., & Lazarus, R. (1980). An analysis of coping in middle-aged community sample. *Journal of Health and Social Behavior, 21*, 219-239.

Folkman, S., & Lazarus, R. (1985). If it changes it must be a process: Study of emotion and coping during three stages of college examination. *Journal of Personality and Social Psychology, 48*(1), 150-170.

Folkman, S., & Lazarus, R. (1988). Coping as a mediator of emotion. *Journal of Personality and Social Psychology, 54*(3), 466-475.

Frey, K., Breenberg, M., & Fewell, R. (1989). Stress and coping among parents of handicapped children : A multidimensional approach. *American Journal of Mental Retardation, 94*(3), 240-249.

Friedrich, W. (1979). Predictors of the coping behaviors of mothers of handicapped children. *Journal of Consulting and Clinical Psychology, 47.*

Friedrich, W.N., Greenberg, M.T., & Crinic, K. (1983). A short-form of the questionnaire on resources and stress. *American Journal of Mental Deficiency, 88*(1), 41-48.

Friedrich, W., Wilturner, L., & Cohen, D. (1985). Coping resources and parenting mentally retarded children. *American Journal of Mental Deficiency, 90*, 130-139.

Friesen, B. J. (1989). National study of parents whose children have serious emotional disorders. In A. Algarin, R. Friedman, A. Duchnowski, K. Kutash, S. Silver, M. Johnson (Eds.), *Children's mental health services and policy: Building a research base.* Tampa, FL: University of South Florida Research and Training Center for Children's Mental Health, Florida Mental Health Institute.

Frijda, N. (1985). Toward a model of emotion. In Spielberger, Sarason & Defares (Eds.), *Stress and Anxiety, 9.* Washington: Hemisphere Publishing.

Gallagher, J.J., Beckman, P., & Cross, A.H. (1983). Families of handicapped children: Sources of stress and its amelioration. *Exceptional Children, 50*(1), 10-17.

Gidden, L.M., Valliere, V.N., & Herbert, S,L. (1988). Adopted children with mental retardation: Positive family impact. *Mental Retardation, 26*(3), 119-126.

Gleason, Karuza, M. & Zeron M. (1981). Adherence to helping models. In Wills (Ed.), *Basic processes in helping relationships*. New York: Academic Press.

Haan, N. (1977). *Coping and defending. Processes of self environment organization*. New York: Academic Press.

Hamilton, M. 1959). The assessment of anxiety states by rating. *British Journal of Medical Psychology, 32*, 51-55.

Hansen, D., & Hill, R. (1964). Families under stress. In H. Christensen (Ed.), *Handbook of Marriage and the Family*. Chicago: Rand McNally.

Hill, R. (1949). *Families under stress*. New York: Harper and Row.

Hill, R. (1958). Generic features of families under stress. *Social Casework, 49*, 139-150.

Hobbs, N. (1975). *The futures on children*. San Francisco: Jossey-Bass. Holroyd, J. (1974). The questionnaire on resources and stress: An instrument to measure family response to a handicapped family member. *Journal of Community Psychology, 2*, 92-94.

Isgard, C. (1984). The primacy of emotions in human development and in human development and in emotion-cognition relationships. In C. Isgard, Kagan, Zajonic (Eds.). *Emotions, cognition and behavior*. New York: Cambridge University Press.

Janoff-Bulman, R., & Frieze, I. (1983). A theoretical perspective for understanding reactions to victimization. *Journal of Social Issues, 39*, 1-17.

Janoff-Bulman, R., & Timko, C. (1987). Coping with traumatic life events. In Snyder & Ford (Eds.), *Coping with negative life events*, New York: Plenum Press.

Kanner, A. et.al. (1981). Comparisons of two modes of stress measurement: Daily hassles and uplifts versus major life events. *Journal of Behavioral Medicine, 4*, 1-39.

Karuza, J. et. al. (1982). Attribution of responsibility by helpers and recipients. In T.A. Wills (Ed.), *Basic processes in helping relationships* (pp. 107-129). New York: Academic Press.

Kemper, T. (1978). *A social interaction theory ef Emotions*. New York: Wiley.

Knafl, K.A., & Deatrick, J.A. (1987). Conceptualizing family response to a child's chronic illness or disability. *Family Relations, 36*, 300-304.

Langer, E.J., & Benevento, A. (1978). Self-induced dependence. *Journal of Personality and Social Psychology, 36*, 866-893.

Lasella, N., & Keogh, B. (1980). Expectations and attributions of parents of handicapped children. *New Directions for Exceptional Children, 4*.

Lazarus, R. (1966). *Psychological stress and the coping process*. New York: McGraw-Hill.

Lazarus, R. (1975). A cognitionally oriented psychologist looks and feed back. *American Psychologist, 30*, 553-561.

Lazarus, R. (1984). On the primacy of cognition. *American Psychologist. 39*(2), 124-129.

Lazarus, R. (1990). Theory-based stress measurement. *Psychological Inquiry, 1*(1), 3-13.

Lazarus, R.S. (1983). The costs and benefits of denial. In S. Breznitz (Ed.), *The Denial of Stress* (pp. 1-30). New York: International Universities Press.

Lazarus, R., & Delongis, A. (1983). Psychological stress and coping in aging. *American Psychologist, 38*, 245-254.

Lazarus, R., Delongis, A., Folkman, S., & Gruen, R. (1985). Stress and adaptational outcomes: The problem of confounded measures. *American Psychologist, 40*(7), 770-779.

Lazarus, R.S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer Publishers Co.

Lazarus, R. & Folkman, S. (1987). Transactional theory and research on emotion & coping. *European Journal Of Personality, 1*, 141-169.

Levinson, R. (1975). *Family crisis and adaptation coping with a mentally retarded child.* Unpublished doctoral dissertation, University of Wisconsin, Madison, WI.

Lourie, N. (1987). Case management. In T.A. Talbott (Ed.), *The chronic mental patient* (pp. 159-164). Washington, DC: American Psychiatric Association.

Mandler, G. (1975). *Mind and emotion*. New York: Wiley. Matheny, K. et al. (1986). Stress coping: A qualitative and quantitative synthesis with implications for treatment. *The Counseling Psychologist, 14*(4), 499-549.

McCubbin, H.I. (1979). Integrating coping behavior in family stress theory. *Journal of Marriage and the Family, 41*, 237-244.

McCubbin, H.I. et. al. (1980). Family stress, coping and social support: A decade review. *Journal of Marriage and the Family, 42*, 855-871.

McCubbin, H.I., Larsen, A., & Olson, D. (1982). F-Copes Family Crisis oriented personal scales. In H. McCubbin & A. Thompson (Eds). (1987), *Family assessment for research and practice*. Madison, WI: University of Wisconsin.

McCubbin, H.I., & McCubbin, M.A. (1987). Family stress theory and assessment: The T-Double ABCX model of family adjustment and adaptation. In H.I. McCubbin & A.I. Thompson (Eds.),*Family assessment inventories for research and practice*. Madison, WI: University of Wisconsin-Madison.

McCubbin, H.I., McCubbin, M.A., Nevin, R., & Cauble, A.E. (1979). Coping health inventory for parents (CHIP). In H. McCubbin & A. Thompson (Eds.), *Family assessment for research and practice.* Madison: University of Madison.

McCubbin, H.I., McCubbin, M.A., Patterson, J.M., Cauble, A.E., Wilson, L., & Warwick, W. (1983). CHIP: Coping health inventory for parents: An assessment of parental coping patterns in the care of the chronically ill child. *Journal of Marriage and Family, 45*, 359-370.

McCubbin, H.I., & Patterson, H. (1981). *Systematic assessment of family stress, resources and coping: Tools for research, education and clinical intervention.* St. Paul, MN: University of Minnesota.

McCubbin, H.I. & Patterson, J.M. (1982). Family adaptation to crisis. In H.I. McCubbin, A.E. Cauble, & J.M. Patterson (Eds.), *Family stress, coping, and social support* (pp. 26-47). Springfield, IL: Charles C. Thomas.

McCubbin, H.I., & Patterson, J.M. (1983). Family transitions: Adaptation to stress. In H.I. McCubbin & C. Figley (Eds.), *Stress and the family: Coping with normative transitions, 1*, (pp. 5-25). New York: Brunner/Mazel.

McCubbin, H.I., Sussman, M.B., & Patterson, J.M. (1983). Introduction. In H.I. McCubbin, M.B. Sussman, & J.M. Patterson (Eds.), *Social stress and the family: Advances and development in family stress theory and research*, (pp. 1-6). New York: Haworth Press.

McCubbin, H.I., & Thompson, A. (1987). *Family assessment inventories for research and practice*. Madison, WI: University of Wisconsin-Madison.

McCubbin, H.I., Thompson, A., & Pirner, P. (1986). *Family rituals typologies and family strengths*. Madison, WI: University of Wisconsin.

McCubbin, M.A. (1987). CHIP: Coping Health Inventory for Parents. In H.I. McCubbin & A.I. Thompson (Eds.), *Family Assessment Inventories for Research and Practice*, 175-190. Madison: University of Wisconsin Press.

McCubbin, M.A. (1988). Family stress, resources and family types: Chronic illness in children. *Family Relations, 37*, 203-210.

McDonald-Wikler, L. (1986). Family stress theory and research on families of children with mental retardation. In J.J. Gallagher & P.M. Vietze (Eds.), *Families of handicapped persons*, (pp. 167-196). Baltimore: Paul H. Brookes.

McLinden-Mott, S.E., & Braeger, T. (1988). The impact on family scale: An adaptation for families of children with handicaps. *Journal of the Division for Early Childhood, 12*(3), 217-233.

McKinney, B., & Peterson, R. (1987). Predictors of stress in parents of develop mentally disabled children, *Journal of Pediatric Psychology, 12*, 133-150.

McNair, D., Lorr, M., & Droppleman, L. (1971). *1971 EITS manual: The profile of mood states*. San Diego: Educational Industrial Testing Service.

Menninger, K. (1963). *The vital balance: The life process in mental health and illness*. New York: Viking.

Nowlis, V., & Nowlis, H. (1956). The description and analysis of mood. *Annals of the New York Academy of Science, 65*, 345-355.

Olson, D. (1986). Circumplex model VII: Validation studies and Faces III. *Family Process, 25*, 337-351.

Ortony, A., & Close, G. (1981). Disentangling the affective lexicon. In *Proceedings of the Third Annual Conference of the Cognitive Science Society*, Berkeley, CA.

Patterson, J.M. (1988). Families experiencing stress: The family adjustment and adaptation response model. *Family Systems Medicine, 5*(2), 202-237.

Pedhazur, E. (1982). *Multiple regression in behavioral research*. New York: Holt, Rinehart and Winston.

Plutckik, R. (1980). *Emotion: A psychorolutionary synthesis*. New York: Harper & Row.

Plutckik, R. et. al. (1970). Reliability and validity of a scale of assessing the functioning of geriatric patients. *Journal of the American Geriatrics Society, 18*, 491-500.

Plutckik, R., Platman, S., & Fieve, R. (1968). Repeated measurements in the manic-depressive illness: Some methodological problems. *Journal of Psychology, 70*, 131-137.

Pollner, N., & Wikler, L. (1985). The social construction of unreality: A case study of a family's attribution of competence to a severely retarded child. *Family Process, 24*, 241-257.

Schachter, S. (1966). The interrelation of cognitive and psychological determinants of emotional state. In C.D. Speileberger (Ed.), *Anxiety and behavior*. New York: Academic Press.

Schachter, S., & Singer, J. (1962). Cognitive, social and physiological determinants of emotional states. *Psychological Review, 69*, 379-399.

Schultzs, R., & Decher, S. (1985). Long-term adjustment of physical disability: The role of social support, perceived control and self blame. *Journal of Personality and Social Psychology, 48*, 1162-1172.

Silver, R.L., Boon, C. & Stone, M.H. (1983). Searching for meaning in misfortune: Sense of incest. *Journal of Social Issues, 39*(2), 81-102.

Stein, R.E.K., & Riessman, C.K. (1980). The development of an impact-on-family scale: Preliminary findings. *Medical Care, 18*(4), 465-472.

Stone, D., & Neale, J. (1984). New measure of daily coping development and preliminary results. *Journal of Personality and Social Psychology, 46*, 892-906.

Strongman, K. (1978). *The Psychology of Emotion*. New York: John Wiley and Sons.

Taylor, S.E. (1983). Adjustment to threatening events: A theory of cognitive adaptation. *American Psychologist, 38*, 1161-1173.

Taylor, S.E., Lichtman, R.R., & Wood, J.V. (1984). Attributions, beliefs about control, and adjustment to breast cancer. *Journal of Personality and Social Psychology, 46*(3), 489-502.

Taylor, S.E., Wood, J.V., & Lichtman, R.R. (1983). It could be worse: Selective evaluation as a response to victimization. *Journal of Social Issues, 39*(2), 19-40.

Thompson, S. (1981). Will it hurt less if I can control it? *Psychological Bulletin, 90*, 96-101.

Thompson, S.C. (1985). Finding positive meaning in a stressful event and coping. *Basic and Applied Social Psychology, 6*(4), 279-295.

Thompson, S.C., Bundek, N.I., & Sobolew-Shubin, A. (under review). The care givers of stroke patients: An investigation of factors associated with depression.

Tomkins, S. (1981). The quest for primary motives: Biography and autobiography of an idea. *Journal of Personality and Social Psychology, 41*(2), 306-329.

Turnbull, A.P., Behr, S.K., & Tollefson, N. (1986, May). *Positive contributions that persons with mental retardation make to their families.* Paper presented at American Association on Mental Deficiency, Denver, CO.

Turnbull, A. et. al. (1984). *Working with families with disabled members: A family system approach*. Lawrence, KS: Kansas University Affiliated Facility.

Turnbull, A.P., Summers, J.A., & Brotherson, M.J. (1986). Family life cycle: Theoretical and empirical implications and future directions for families with mentally retarded members. In J.J. Gallagher & P.M. Vietze (Eds.), *Families of handicapped persons: Research, programs and Policy issues*, (pp. 45-66). Baltimore: Paul H. Brookes.

Vonkrs, M. (1981). Familial coping with chronic and severe childhood illness: The case of coptic fibrosis. *Social Science Medicine, 15*(A), 289-297.

Weiner, B., Russell, D. & Lerman, D. (1979). Affective consequences of causal ascriptions. In Harvey, Ickes & Kidd (Eds.), *New Directions of Attribution Research, 2*. Hillsdale NJ: Erlbaum.

Wikler, L. (1986). Family stress theory and research on families of children with mental retardation. In J. Gallagher & P. Vietze (Eds.). *Families of handicapped persons: Research programs and policy issues*, (pp. 167- 197). Baltimore: Brookes.

Wikler, L., Wasow, M., & Hatfield, E. (1983, July-August). Seeking strengths in families of developmentally disabled children. *Social Work*, 313-315.

Young, P.T. (1961). *Motivation and emotion*. New York: Wiley.

Zajonc, R.B. (1984). On the primacy of affect. *American Psychologist, 39*(2), 117-123.

Zubin, J., Eron, L., & Schumer, F. (1965). *An experimental approach to projective techniques*. New York: Wiley.

Zukerman, M., & Lubhin, B. (1965). *Manual for the Multiple Affect Adjective Check List*. San Diego: Educational and Industrial Testing Service.

# Building a Conceptual Model of Family Response to a Child's Chronic Illness or Disability

## EVALUATION FORM

1. Who used the monograph? (Check all that apply.)

___Parent ___Educator ___Child Welfare Worker

___Juvenile Justice Worker ___Mental Health Professional

Other (Please Specify)_____

2. Please describe the purpose(s) for which you used the monograph:

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_____

3. Would you recommend use of the monograph to others? (Circle one)

Definitely Maybe Conditionally Under No Circumstances

Comments:_____

4. Overall, I thought the monograph was: (Circle one)

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Comments:_____

5. Please offer suggestions for the improvement of subsequent editions of this monograph:

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