A Conceptual Model to Examine the Relationship Between the Health Status of School Age Children with Cystic Fibrosis and the Hassles Reported by These Children and Their Families

by

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ABSTRACT

A CONCEPTUAL MODEL TO EXAMINE THE RELATIONSHIP BETWEEN THE HEALTH STATUS OF SCHOOL AGE CHILDREN WITH CYSTIC FIBROSIS AND THE HASSLES REPORTED BY THESE CHILDREN AND THEIR FAMILIES

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The conceptual framework developed in this scholarly project can be used to assess the impact of family hassles on the health of school age children with cystic fibrosis (CF). Treatment of CF is intensive, lifelong, and expensive, and the median life expectancy is age twenty. Consequently, families with CF children undergo many stressors, ranging from major life events to daily hassles. Recent work has shown that hassles may be more important than major life events in predicting health status. The proposed framework evolves from both family and systems theories. Longitudinal data are collected from family members regarding the occurrences of events of events/non-events, and their assignment as non-hassles, hassles, or crises. Both cumulative and weighted hassles scores can be obtained. Unsuccessful efforts to manage these events/non-events takes energy from the family system, possibly negatively impacting health. Health is measured using the Swachman score and other indices. Nurses in advanced practice intervene to decrease occurrences of hassles, or facilitate individual and family adjustment to them.

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CHAPTER I

Introduction

It is virtually impossible today to read literature from the biological and social sciences without coming across the terms stress and stressors. Indeed, even popular lay readings are replete with references to these concepts, and one can purchase vitamin complexes which are called "Stress-tabs". Everyone is aware that life in today's society is stressful, and management of stress has become a popular focus of programs designed to help improve health.

A stressor is defined as any stimulus that requires an organism to make corresponding changes (Lazarus, 1984), and no organism could live without some stressors. Hunger, for example, is a stressor which motivates humans to search for food for survival. The sensation of cold is an unpleasant stressor which prompts one to dress warmer, or to warm the environment to protect the body from damage. At a more complex level, an impending exam serves as a stressor which motivates students to study to pass a course.

But in today's complex society, many stressors do not serve a useful purpose, and the sheer number of stressors encountered by individuals may overwhelm the capacity to respond. The result is a heightened level of stress which might have a negative effect on the life and health of individuals. It is this high stress level that is of interest to nurses who are concerned with the relationship of stress to health outcome.

In the past, many researchers have studied the possible link between health status and life events, or stressors, experienced by individuals or groups of individuals (Dohrenwend, 1974; Engel, 1977; Glass, 1977; Holmes and Rahe, 1967; McCubbin, Wilson, and Patterson, 1979; and Parkes, 1972). Their studies have looked primarily at stressors in the form of major life events which effect change in the individual's objective environment. More recently, "micro-stressors", or "hassles" have emerged as potent sources of stress, which can have a negative effect on the health of individuals (DeLongis, Coyne, Dakof, Folkman, and Lazarus, 1982; Jandorf, Deblinger, Neale, and Stone, 1987; and Kanner, Coyne, Schaefer, and Lazarus, 1980).

Hassles, in the literature, are defined as irritating, frustrating, and distressing demands, present in every day transactions with the environment, and include annoying, practical problems such as misplacing things, getting caught in traffic jams, or breaking a shoelace (Kanner et al, 1980). All persons--children and adults--experience hassles in their daily lives. These hassles, though seemingly insignificant at the time of their occurrence, may actually impact on health outcomes of individuals.

Little research has been conducted to examine whether there is a relationship between hassles experienced by family members and the health of an individual family member (DeLongis et al., 1982; Jandorf et al., 1987; Kanner et al., 1988; and Walker, Ford, and Donald, 1987). Yet leading family researchers contend that what happens to one family member has an indirect effect on all family members (Hill, 1949; McCubbin and Figley, 1983; Miller and Janosik, 1980; and Walsh, 1982). One can assume, then, that stressors experienced by individual family members may have a negative effect on the health of not only that member, but the other family members, as well.

Families of children with chronic illness are known to experience more stressors than families without chronic illness (McCubbin and Patterson, 1983). If we include hassles as stressors, can we assume that these hassles have a deleterious effect on the health of a child with cystic fibrosis (CF), leading to an escalation of symptoms? If this is the case, perhaps interventions to lessen the incidence or significance of daily hassles could indeed improve both quality and quantity of life for CF children and their families.

The purpose of this scholarly project is to develop a conceptual framework to be used in assessing whether or not a relationship exists between the physical health status of children with CF and hassles reported by these children and their families. This framework will enable researchers to study individual family member's responses to hassles, rather than assume that responses made by parents are truly reflective of family hassles. If hassles experienced by all family members are shown to negatively influence CF children's health, appropriate family-centered interventions can be undertaken by the clinical nurse specialist (CNS) in advanced practice.

In the remainder of chapter one, basic concepts important to the question of a hassles-health relationship will be discussed, and these concepts will be defined. An historical perspective will be provided to assist the reader in understanding the evolution of care and prognosis for children with CF. This perspective will also demonstrate the emergence and progression of research concerned with the relationship between stress and health.

In chapter two, a thorough review of the literature will be undertaken to facilitate the integration of basic concepts in the conceptual framework which follows. The literature reviewed will be critiqued for its relevance to the purpose of this project. Strengths, as well as weaknesses of the current literature from the topic area will be delineated.

Following the literature review, a conceptual framework will be proposed in chapter three. This framework will be derived from the original work by Hill (1949), who was a pioneer in looking at the effects of stress on the family. The model will be modified according to the work of Lazarus and Folkman (1984) and McCubbin (1983).

In the fourth and final chapter, Imogene King's theoretical framework for nursing will be utilized to explain the relevance of the question under consideration to nursing practice. The various roles of the CNS in primary care will be explored. The conceptual framework will be utilized to explain the role of the CNS in caring for families of children with CF.

Cystic Fibrosis--The Disease

CF is the most common genetic cause of death in the Caucasian population in the United States, with an occurrence of 1:1600 live births (Whaley and Wong, 1989). The mode of transmission is autosomal-recessive, which means that both parents are asymptomatic carriers of the disease. Two carrier parents have a 1:4 chance of producing a child with CF with each pregnancy. They also face a 2:4 chance, with each pregnancy, of bearing children who themselves carry the CF gene. The carrier rate in the Caucasian population is 5% (Taussig, 1984).

Although CF is a multisystem disorder, it is characterized primarily by chronic obstruction and infection of the airways, and by maldigestion and its consequences (Nelson and Vaughan, 1987). These manifestations are caused by viscous mucus, which leads to mechanical obstruction of the airways and pancreatic ducts. The production of this thick, inspissated mucus results from widespread dysfunction of the exocrine glands. Children with CF, then, most frequently present in early life with repeated respiratory infection and poor growth curves secondary to the lack of pancreatic enzymes essential to the digestion of foodstuffs (Taussig, 1984).

Additional manifestations of CF include nasal polyps, which are reported in 6% to 24% of patients with CF (Rosenstein and Langbaum, 1985). Hypoprothrombinemia may be present due to vitamin K deficiency, possibly leading to a bleeding disorder. Intussusception, an obstructive condition caused by telescoping of the bowel, occurs in some children. Chronic constipation is common, and may lead to bowel obstruction (Rosenstein and Langbaum, 1985).

During adolescence and young adulthood, male aspermia and decreased female fertility are classic presentations (Rosenstein and Langbaum, 1985). Additionally, 40% to 60% of affected individuals eventually develop diabetes mellitus. Fortunately, even though this diabetes requires insulin replacement, it is fairly easily controlled (Taussig, 1984).

Individuals with CF experience repeated respiratory infections. Bronchopulmonary infections are the major determinant of morbidity and mortality (Stutman and Marks, 1987). Because children with CF are chronically hypoxemic, clubbing of the nailbeds occurs, and cor pulmonale eventually develops as the right side of the heart struggles to pump blood against great resistance in the damaged lungs (Allen and Lemen, 1985). These children are smaller in stature than their healthy counterparts, develop barrel chests, and are delayed by about two years in their sexual development (Dibble and Savedra, 1988).

Presently, there is no cure for CF (Levison, Garner, MacMillan and Cowen, 1987). Additionally, screening measures to test the general public for the carrier state do not exist. Some recent advances, as described by Kane (1988), allow antenatal, first trimester testing for CF. but this testing is usually suitable only for couples with a 1:4 risk of bearing an affected child--those who have already had a child with CF.

In summary, CF has been shown to be a disease dependent upon genetic transmission, Presently, no means exist for the wide-spread testing for the carrier state. CF is a multisystem disorder, but the most serious effects are on the respiratory system. It is this respiratory involvement which ultimately is the cause of death for children afflicted with this incurable disease.

Historical Perspectives of CF

Although CF was not described as a specific disease entity until the 1930s, one can find references to infants and children with probable CF in earlier literature. Schmidt (1729), in compiling a text of folk philosophy, wrote that a salty taste meant that a child was bewitched. In the mid-1800s, Pfyffer (1848) stated "If it tastes salty when someone is kissed on the brow, then this person is hexed", and Rochholz (1857), in the Almanac of Children's Songs and Games from Switzerland noted that "the child will soon die whose brow tastes salty when kissed". These statements all refer to the hallmark of CF diagnosis, ie. increased levels of sodium and chloride in the sweat of these individuals.

In literature from the early 1900s, one finds multiple references to children with likely CF. Meconeum ileus and pancreatic pathology were reported by several authors (Anderson, 1930; and Dodd, 1936).

Many of these children were recognized to have associated respiratory changes, such as chronic bronchitis and bronchiectasis.

In the 1930s, CF was recognized as a specific disease entity. Although several authors described the multiple manifestations of this disorder, Andersen (1930) was the first to label the disease CF. Andersen's work was descriptive of both the pancreatic findings and the pathological changes in the lungs. In 1946, Andersen and Hodges proposed the currently accepted autosomal-recessive inheritance pattern for CF.

di Sant' Agnese described the high concentrations of sodium and chloride in the sweat of affected individuals in 1953. These sweat electrolyte abnormalities were the basis for the development of the sweat chloride test and the subsequent quantitative pilocarpine iontophoresis test, the latter of which is currently the definitive diagnostic test for CF.

In 1946, di Sant' Agnese and Andersen first studied the use of antibiotics in treating lung disease in individuals with CF. Some physicians prescribed antibiotics prophylactically on a continuous basis, while others advocated their use only for acute exacerbations of pulmonary infections (Swachman and Kulczycki, 1958).

Even before the description of CF as a disease entity, exogenous pancreatic enzyme preparations, derived from hog pancreas, were being administered as early as 1904 to treat recognized pancreatic insufficiency. Andersen (1945) described the use of pancreatic extracts to improve digestion, resulting in reduction of stool weight and fat excretion for patients with pancreatic deficiency. Andersen (1945) also stressed the importance of a high calorie, high protein diet.

The life expectancy for children with CF was initially very bleak, and in 1948, no known CF patients survived into adolescence (Levison, Garner, MacMillen, and Cowen, 1987). But by 1966, the median age of survival with CF was 12 years. Currently, the median life expectancy is approximately 23 for women, and 28 for men (MacLusky, McLaughlin, and Levison, 1985). Despite the impressive advance in treatment and life expectancy, however, the fact remains that a cure for this devastating disease remains elusive, and affected individuals and their families are continuously barraged by stressors related to the disease itself, and the complexities of its treatment.

Treatment of Cystic Fibrosis

The aforementioned improvement in life expectancy for children with CF is largely credited to early diagnosis and treatment (Whaley and Wong, 1987; and Wilcken and Chalmers, 1985). At the time of diagnosis, a treatment regimen is initiated which is life-long in nature. Chest physical therapy (CPT), a combination of aerosolized medication, percussion, and postural drainage, is instituted on a twice or more daily basis to help loosen and eliminate viscous bronchial and bronchiolar secretions (Taussig, 1984). CPT is typically carried out in the home by the parents, and takes a time committment of one to two hours, every day of the child's life. If the child is cared for by others, they, too, must learn CPT to ensure that the child receives these necessary treatments. Relapses in following through with CPT tend to result in a worsening of the child's pulmonary status (Zack and Oberwaldner, 1987).

As the child reaches adolescence, mechanical vibrators are sometimes used to allow for self-CPT, thus relieving some of the time commitment by the parent (Zack and Oberwaldner, 1987). The use of self-CPT also gives adolescents a sense of control, decreases dependence on others, and promotes self-care. Self-CPT, however, does not lessen the fact that parents still have to monitor the adolescent to make certain that treatments are carried out. This is not a small task, when one considers that adolescents are striving for independence, and sometimes discard interventions that they perceive as promoting the dependent role (Whaley and Wong, 1989).

During an acute pulmonary exacerbation, which is accompanied by respiratory infection, children are hospitalized for 10 to 14 days for intensive intravenous (IV) antibiotic therapy, nutritional therapy, and CPT (Taussig, 1984; and Whaley and Wong, 1989). Although hospitalization lessens the parents' direct responsibility for the daily care of the child, it substitutes new stressors, in the form of financial concerns, time and transportation to visit the hospitalized child, sibling jealousy at the attention paid to the sick child, and increased worry by parents as they are confronted again with the ultimately fatal nature of CF.

Another major aspect of the life-long treatment regimen is that of optimizing the child's nutritional status. A diet is prescribed which is higher in calories and protein than is required by an unaffected child of the same age, and the diet is supplemented with iron and vitamins, especially fat soluble vitamins A, E, and K (Dodge, 1988). The increased caloric intake in CF is required to compensate for losses due to malabsorption, and to allow for catch-up growth, when necessary (Dodge, 1988). With advanced pulmonary disease, there are additional caloric requirements to fight infection, and for the increased work of breathing. Together, these factors add up to a daily need for 120-150% of the recommended daily allowance of calories for optimum growth and homeostasis (Dodge, 1988).

These increased nutritional needs are met in two ways. First, additional oral intake is encouraged in the form of well-balanced, high calorie meals and frequent nutritious snacks (Dodge, 1988). For infants, special easily digested formulas are used (Nelson and Vaughan, 1987). If oral intake is insufficient to meet metabolic needs, nightly feedings, either through naso-gastric, gastrostomy, or jejunostomy tubes may be instituted as part of the child's home therapy. These supplemental feedings require nightly placement of a naso-gastric tube by parents, or surgical placement of gastrostomy or jejunostomy tubes with nightly hook-ups to feeding bags (Whaley and

Wong, 1989). The procedure itself may make children feel dependent and different. Parents may get less sleep, and also may feel more confined to the home. Siblings might be frightened by the visible change in body image of their affected brother or sister.

The second means to meeting the nutritional needs of children with CF is by administering from 1 to 10 capsules of exogenous pancreatic enzymes with all meals and snacks to facilitate the digestion and absorption of ingested food (Dibble and Savedra, 1988; and Taussig, 1985). Success of this intervention is measured by weight gain in the child, and a decrease in bulky, fatty, foul smelling stools which result when food passes through the body, rather than being digested and absorbed (Taussig, 1984).

The nutritional demands for children with CF are almost exclusively the responsibility of parents. Meals must be carefully planned and supervised, and medications (enzymes, vitamins, and iron) must be monitored. If eating away from parents, such as at school or at the home of friends, the children themselves must take the responsibility for taking necessary medications. They may see themselves as different, and this difference is accented in social interactions where the sheer volume of medications results in an awkward situation around the sharing of meals. Children may cope with this dilemma by not eating, or by not taking their replacement enzymes (Dibble and Savedra, 1988). Both behaviors result in calories lost either through malabsorption or omission.

At CF clinics where food supplementation is instituted at an early age, statistics show an improved survival status (Corey, 1980; Dodge, 1988; and Shepherd, Cooksley, and Cooke, 1980). This knowledge often leads to a situation in which food becomes a battleground in the parent-child relationship. This author, who has had ten years experience in caring for children in a CF research center, has frequently seen parents of newly diagnosed infants force-feed them to the point of regurgitation. As children develop, they quickly perceive parental anxiety over food intake. Again, this author has observed numerous instances where children have become skilled at manipulating parental behaviors by refusing to eat what parent think they should.

The trend in the United States toward home health care (Whaley and Wong, 1989) will no doubt have an impact on family functioning and resulting stressors for families with CF children. For example, in the past, all children were hospitalized when they needed IV antibiotics during an acute exacerbation of pulmonary status (Hodson, 1984). With advances in home care, however, it is now possible for children to receive necessary IV antibiotics in their own home via surgically implanted indwelling catheters (Nelson and Vaughan, 1987). Typically, more than one antibiotic is prescribed (Doring, Albus, and Hiby, 1988), which means IV doses of medication every 3 to 4 hours around the clock for at least 10 to 14 days during periods of exacerbation. Involved parents will have to learn a new, fairly complex skill. Sleep patterns will be disrupted. Time for parents to spend with siblings will be curtailed, as will available energy. The overall impact on the family is obvious.

Throughout this paper, the author deals primarily with manifestations of CF involving the digestive and respiratory systems. The reader must remember that additional manifestations may be experienced as described earlier. The manifestations include nasal polyps, cor pulmonale, decreased fertility, sterility, diabetes mellitus, constipation, and intussusception. Any one of these would add stressors to CF children and their families.

Stressors and Cystic Fibrosis

In the preceeding discussion of CF, it has been established that families with CF children experience many stressors. Since the care of these children occurs primarily in the home, families shoulder the major responsibility for the routine management of the illness (Walker, Ford, and Donald, 1984). The ongoing, never-ending nature of this care many deplete resources of time, money, and energy.

CF is a chronic disease that may produce unique psychological and social problems in patients and families. Parents often express guilt over their role in the hereditary nature of a disease which ultimately leads to the untimely death of their child. Although 50% of affected children reach the mid-twenties, 50% do not (MacLusky, McLaughlin, and Levison, 1985). These factors together make many parents reluctant to enforce uniform and reasonable discipline, or to encourage "normalcy" in the children. Additionally, parents may not enforce adherence to the strict treatment regimen, particularly when the child is resistant, because "the child is going through so much already" (Whaley and Wong, 1989).

The treatment of CF is time consuming and exhausting, and disrupts the already established patterns of family functioning. Role boundaries and their associated responsibilities will change, as family members assume varying degrees of care of the child, or take on new tasks to help ease the increased workload (Miller, 1980; and Walsh, 1985). Involved parents will have less time for each other, and siblings may resent the fact they they no longer receive as much parental attention as they received prior to the diagnosis of CF. The affected child might perceive that he is a burden, and assume a large measure of guilt, which in itself, is an added stressor.

Family finances may be taxed in providing the special equipment, food, and medications needed by children with CF. Mothers may feel the need to work outside the home to help with finances, but be unable to do so because of their perceived need to be with the child. Frequent trips to the nearest CF treatment center, and hospitalizations add to the financial burden. With more and more of these children reaching adulthood, and moving out of their family homes to become productive members of society, a new problem emerges, in that health insurance becomes difficult to obtain.

The ongoing, continuous nature of CF treatment imposes daily reminders of the illness on the family and affected child. There is no end in sight. Treatment terminates only at the time of death.

Children with CF are constantly confronted with the fact that they are different from their peers. Pancreatic enzymes must be taken at all meals and with snacks. Typically, CPT is performed on a twice or more daily basis. This specialized treatment makes these children different, and may prohibit them from participating in the same activities as other children. Overnight experiences, including pajama parties, school excursions, and usual camping experiences might not be possible. Participation in physically active events is hindered by decreased stamina, and children may need to be excused from regular gym or recess activities. Boys who dream of being star football players soon find that their dream is unattainable. Frequent respiratory infections may cause these children to miss school, and possibly, to lose their place in the peer group. Small body stature and chronic cough may interfere with the development of a positive body image.

Recognizing that CF imposes many stressors on children and their families, numerous researchers have focused their efforts on the study of the effects of the stressors (Cowen, Corey, Keenan, Simmons, Arndt, and Levison, 1985; McCubbin, McCubbin, Patterson, Cauble, Wilson, and Worwick, 1983; and Stullenbarger, Norris, Edgil, and Prosser, 1987). But most of these researchers have not truly looked at the effects of the stressors as reported by individual family members. Rather, the focus has been placed on parental perceptions, particularly the perceptions of the mother, as to what stressors are being experienced by individual family members, and what their effects might be. But in keeping with family systems theory (Walsh, 1985), the family must be viewed as an interdependent system, in which changes in one member impact on all other members. Systems seek to maintain equilibrium in response to internal and external stressors. Families of CF children are constantly faced with stressors, and the ongoing hardships imposed by them may make it difficult to maintain equilibrium.

Assuming a family systems theory approach, it is quite evident that studies which address family functioning in CF are critical in determining how health care providers can best serve family needs. Indeed, the majority of care for children with CF occurs in the home and is provided by the family. Therefore, the concept of family response to stressors becomes a central issue, particularly to the CNS in primary care.

Hassles and Health

The majority of studies of stressors in family functioning have looked at stressors as major life events which affect change in an individual's objective environment, and it is accepted that an increase in life events has a negative impact on the health of individuals (Hyman and Woog, 1982; and Smith, Gad, and O'Grady, 1986).

But recently, there has been recognition that micro-stressors, or hassles, acting cumulatively, or piling up, can also be potent sources of stress (Kanner, Coyne, Schaefer, and Lazarus, 1980; Lazarus and Folkman, 1984; and Patterson and McCubbin, 1983). Hassles are conceptualized as irritating, frustrating, distressing demands that are present in everyday transactions with the environment, and include annoying practical problems such as misplacing things, getting caught in traffic jams, or breaking a shoelace. Hassles occur in the lives of both children and adults, and, if they accumulate, they are energy depleting. The results of some research suggest that individuals who experience many hassles, or who perceive that the hassles they experience will require much adjustment, do indeed experience negative effects on their health (Lazarus and Folkman, 1984; and Zautra, Guarnaccia, and Dohrenwend, 1986).

Examples of hassles might be misplacing the car keys, and finding that one does not have clean underwear on a particular morning. If these hassles occur on the day of an early morning appointment at the CF center 30 miles away. they are likely to pile-up with other stressors associated with getting to the appointment on time. Thus, they will be more troublesome than if they had occurred on a day when nothing in particular was scheduled.

The preceding statement leads to an important consideration, ie. "Do hassles affect health if they are not perceived to be stressful?" It is common knowledge that the same stressor (hassle) evokes different responses in different individuals. And the same stressor (hassle) evokes differing responses in the same individual when it occurs at different times under different circumstances. Folkman and Lazarus (1984) attribute these differences to cognitive appraisal, a process whereby individuals evaluate stressor situations according to how much these situations tax or exceed their adaptive resources (p. 27). A conceptual model which is developed to look at the relationship between family hassles and health of children with CF must allow evaluation of both the occurrence and the perceived threat of these hassles to individuals.

It is important that health care providers be sensitive to the hassles reported by CF children and their families so appropriate support can be provided. The depletion of energy which might occur from dealing with hassles takes away potential energy for meeting the demands of the disease and its treatment. Ultimately, this depletion of energy contributes to a decline in the health of these children.

Traditionally, there are more avenues of support available for major life events than for hassles. But if it is found that hassles are an important contributing factor to health status, support must also be provided during these seemingly insignificant occurrences. In addition to receiving support, these families must be helped to develop the skills necessary to decrease hassles, and to deal with the hassles which are unavoidable. If the concept of hassles is viewed in the context of family systems theory, it becomes clear that hassles experienced by all family members must be considered when the CNS proposes interventions which are aimed at optimizing the CF child's health.

Cystic Fibrosis as a Prototype of Chronic Illness

Although CF is ultimately fatal, it is regarded as a chronic disease (Taussig, 1985). Since it is commonly diagnosed in the first year of life, CF represents a formidable adversary that affects family functioning on a daily basis. Its genetic property might be expected to lead to parental guilt or blame. The bulk of the required treatment is administered in the home, thereby requiring changes in familial role functioning. Many children survive into young adulthood or beyond, and thus have to pass through each developmental state "under the influence" of CF. Similarly, the family, as it passes through its own life cycles, will be affected by the presence of a member with CF (Rolland, 1987).

CF is a relapsing illness, characterized by remissions and exacerbations (Taussig, 1984). The distinguishable feature of this kind of illness is the alternation of relatively stable periods of varying length, characterized by a low level or absence of symptoms, with periods of flare-up or exacerbation, often leading to hospitalization (Taussig, 1984). Strain on the family system is caused by both the exacerbation itself and the ongoing uncertainty of when an exacerbation is going to occur. A critical component is family flexibility that permits movement back and forth between two forms of family organization.

The uncertainty of how CF will progress with any given child is an important concept for the CNS to consider. Uncertainty occurs in a situation in which an individual is unable to assign definite meaning or value to events, and cannot predict outcomes. Mishel (1981, 1988) demonstrated that uncertainty is associated with increased anxiety, depression, and pessimism about the future. These outcomes may interfere with the family's ability to deal with stressors, and, in the case of CF, may have a negative impact on the health of these children.

The fact that CF ultimately shortens one's life is a feature which has profound psychosocial impact. The "It could happen" nature of CF creates the possibility of over-protection by the family. The ill member may manipulate other family members for powerful secondary gains (Whaley and Wong, 1989).

For researchers interested in studying the relationship of family functioning and chronic illness, CF is a single disease entity which profoundly impacts all aspects of the family over a long period of time. Meyerowitz and Kaplan (1967) bemoaned the fact that, as a chronic illness, CF had received little attention from investigators of family functioning. Since Meyerowitz's and Kaplan's classic study, however numerous researchers have realized that families with a CF member represent a very fertile area of study, and one can now find numerous related books and articles in the literature (Dibble and Savedra, 1988; Gayton, Friedman, and Tavormina, 1977; Holroyd and Guthrie, 1986; Lewiston, 1985; Matthers, 1984; McCubbin and Patterson, 1983; and Orenstein, 1985).

From the preceding discussion, it is clear that families of children with CF experience a multitude of stressors over the child's lifetime. These stressors are experienced by all members of the family, and their impact is continued throughout individual and family developmental stages. For these reasons, CF represents an ideal prototype disease when one is concerned about the possible relationship of hassles to the health of chronically ill children. Additionally, and from a more practical point of view, research in this area is facilitated by the fact that children with CF are typically seen at regular intervals at regional CF centers. Thus, they represent a population that is fairly easy to access for study purposes.

Relevance of this Project to Nursing Practice

Nursing has been defined as "the diagnosis and treatment of individual and family responses to actual or potential health problems" (American Nurses Association, 1980). CF is an actual health problem which demands expert nursing care. But it is also a disease which is associated with potential health problems as it progresses over time. These potential health problems impact the physical, psychosocial, and spiritual arenas for all family members. The CNS has a special interest in helping family members cope with these actual and potential health problems.

There exists a substantial body of research which shows a relationship between stressful situations and physiologic responses in the body (Cannon, 1929; Cohen and Lazarus, 1983; and Selye, 1957). In explaining this relationship, it is assumed that the human body attempts to maintain homeostasis when confronted with internal or external change. Any circumstance which upsets the body's steady state calls for adjustment, and any adjustment attempts require energy (Bargagliottli and Trygstad, 1987; and Patterson and McCubbin, 1983).

Because hassles represent departures from usual patterns of functioning, dealing with them requires an expenditure of energy. This expenditure of energy occurs as the individual attempts to achieve equilibrium. However, if hassled, individuals may not have the time or energy for self-care. CF children and their families have had their energy taxed greatly already--children because of their impaired nutritional and respiratory status, and families because of increased expenditures of time, finances, and physical and psychological stamina.

The CNS in primary care must understand the effects that daily hassles have on CF children and their families if she wishes to provide the most therapeutic interventions. When these effects are understood, the CNS directs her efforts toward helping families decrease their exposure to hassles. For those hassles that are unavoidable, she facilitates family adaptation to them with the least amount of energy expenditure.

Traditionally, nursing intervention in CF has been in direct proportion to the sickness of the child; ie. the sicker the child, the more the nursing interventions (Meyerowitz and Kaplan, 1967). It might be true, however, that when children are sicker and confined largely to the home or hospital, parents would feel more in control and less anxious than when children are less sick and attending "normal" childhood functions away from home (Meyerowitz and Kaplan, 1967). Attendance at school and associated activities, clubs, and visiting friends may cause more anxiety in parents because they can't control and supervise everything their children are supposed to do--or not do--such as taking pancreatic enzymes with meals, avoiding excess physical activity, shunning contact with persons with respiratory infections, and staying away from cigarette or other smoke. Consequently, when children are sicker, and more under the direct control of parents, fewer hassles might be reported.

If it is true that parents report more instances of hassles when children are less sick, nurses must intensify interventions in the earlier stages of the disease. Appropriate interventions might take the form of anticipatory guidance, and the development of problem-solving skills. This early intervention could promote positive family functioning, which may possibly decrease the amount and intensity of hassles experienced at a later time.

The assumption that families may need more nursing interventions when CF children are less sick and under less parental control than when they are sicker and under more parental control is based on the early work of Meyerowitz (1967) cited in a previous paragraph. Their research is considered classic in childhood chronic illness literature, and no more recent work investigating the relationship of parental control and the anxiety they report was found by this author. Obviously, the relationship between health and activity status, and perceived parental control of the situation is an area which needs further research, especially by nurses in advanced practice who care for these families.

Definition of Concepts

Hassles Traditionally, stressors have been defined as those life events and related hardships that are of sufficient magnitude to bring about change in the family system (Burr, 1973; Hill, 1949; and Walsh, 1985). Stressors are life events or transitions which impact on the family unit and produce change in the family social system (McCubbin and Patterson, 1983). These stressors and their impact have been measured as major life events (Dohrenwend and Dohrenwend, 1974; and Holmes and Rahe, 1967).

Assessing major life events, however, reveals little about the process of day to day interactions of individuals with their environment. This day to day interaction with one's environment is fraught with relatively minor stressors that can be potent sources of stress. These seemingly insignificant stressors have been labeled "hassles". Hassles are defined in the literature as "the irritating, frustrating, distressing demands that, to some degree, characterize everyday transactions with the environment"(Kanner et al, 1980, p. 3). Kanner's definition of hassles will be utilized throughout this scholarly project.

Cystic Fibrosis Earlier in this paper, CF was defined as a multisystem disorder, characterized primarily by chronic obstruction and infection of the airways, and by maldigestion and its consequences (Nelson and Vaughan, 1987). CF is ultimately fatal, and the median age of survival is the mid-twenties (MacLusky, McLaughlin, and Levison, 1985). As an autosomal-recessive disease, both parents must be carriers, and they run a 1:4 risk of producing a child with CF with each pregnancy. Currently, there is no cure for CF, and testing for the carrier state is not available to the public (Kane, 1988).

The definitive diagnosis of CF is made using the quantitative pilocarpine iontophoresis test (Taussig, 1984). This test should be performed whenever clinical symptomatology indicates the need to rule out CF. The test should also be performed on all children who are at high risk, ie. have a sibling with diagnosed CF. The test is considered positive if sweat chloride levels are above 60 mEq/liter. Children with CF, when discussed in this paper, are children who have had quantitative pilocarpine iontopheresis chloride levels in the diagnostic range.

Health Status The World Health Organization defines health as a state of physical, mental, and social well-being, and not merely the absence of disease or infirmity (Detwiller, 1984, p. 88). Terris (1975) expands this definition in asserting that "health is a state of physical, mental, and social well-being and ability to function, and not merely the absence of illness or infirmity" (p. 1037). Imogene King, in her theory for nursing (1981), defines health as the "dynamic life experiences of a human being, which implies continuous adjustment to stressors in the internal and external environment through optimum use of one's resources to achieve maximum potential for daily living" (p. 5). All three of these definitions point to a holistic orientation, rather than simply looking at physical parameters. King's definition, however, contains the added dimension of continuous adjustment to stressors in the environment, and that seems to more accurately portray the view of health that will be developed in this authors conceptual framework which follows in Chapter III. Therefore, King's definition of health will be used throughout this paper.

Health is a major concept in the question posed in this paper, ie. Is there a relationship between the health status of school-aged children with CF and the hassles experienced by these children and their families? Consequently, it is necessary to know how the concept of health can be measured. The tool which is most widely used to measure the health of children with CF is the Swachman and Kulczycki (1958) rating scale. Using this scale, CF children are categorized according to participation in activities, physical exam findings, nutritional status, and chest x-ray findings.

At first glance, this scoring system appears to neglect the psychosocial dimensions of the effects of CF. But on closer look, it is seen that an assessment of the general activity of these children provides some information about their psychosocial adjustment to CF. Peers are extremely important to school-age children, and participation in school and other age-related activities assures interactions with peers, to a lesser or greater extent. For that reason, children who score fairly well on the strictly physical parameters of CF would receive a lower over-all score for health if their parents were keeping them out of school for one reason or another. Probably, children who are more active perceive their health status to be better than if they are not participating in usual activities.

In devising their scoring system, Swachman and Kulczycki (1958) followed one hundred five children with CF for a five- to fourteen-year period of time. Variables of CF treatment were not manipulated in their study; rather, the health of these children was measured at three month intervals to provide descriptive data as to how they progressed with the disease. It appeared from their writing, however, that Swachman and Kulczycki managed their CF children in very similar ways, keeping the effect of varying treatment modalities at a minimum.

The children in the study were followed for at least five years to a maximum of fourteen years. This longitudinal method of data collection allowed for a determination of the variables of general activity, physical exam findings, nutritional status, and chest x-ray findings as the disease progressed over time or ultimately caused death. The authors were able to develop diagnostic criteria for each of the four categories of variables. A ranking of severity of disease involvement was determined for each category, ranging from minimal (86-100 points) to severe (under 40 points). The Swachman-Kulczycki scoring system appears in Appendix A of this paper.

Swachman and Kulczycki were able to show that children with CF showed varied speeds of deterioration. The health of some children declined very rapidly, while others remained stable for long periods of time. Therefore, the Swachman-Kulczycki scoring system is used not so much as a prognostic indicator, but rather it serves as a means to clinically and consistently categorize CF children at any given stage of their disease. From a research perspective, this clinical categorization allows researchers to study the relationship of different variables to the health of the children. Treatment modalities, both physical and psychosocial, can be manipulated, and life experiences can be measured, to see if there is a corresponding change in health status, both long- and short-term. For these reasons, the Swachman-Kulczycki scoring system can be used to study the possible effects of family hassles on the health of children with CF. Because the Swachman-Kulczycki scoring system tests primarily physical parameters of health, however, other scales will also be used to give a holistic perspective of health measurement, inclusive of psycho-social factors.

Children with CF For the purposes of this project, children will be defined as those age seven through eleven years. According to the psychologist, Jean Piaget (1977), children of this age are becoming increasingly logical and coherent in thought. They are able to classify, sort, order and organize facts about the environment to use in problem solving, but still in a very concrete way. They are able to deal with several different aspects of a situation simultaneously (Piaget, 1977). Children of this age are generally enrolled in school grades two through six, and are developing reading and writing skills. All of these intellectual capacities are important considerations when devising a tool for data collection.

Socially, these children are ready to move away from the family for varying periods of time into an environment where peers become increasingly important. School presents an arena for children to engage in experiences and relationships outside the family (Whaley and Wong, 1989).

A sense of accomplishment is achieved somewhere between seven years of age and adolescence (Whaley and Wong, 1989). This sense involves an eagerness for participation in meaningful and socially useful work. Interests expand in these middle years, and with a growing sense of independence, children want to engage in tasks that can be carried through to completion. Much satisfaction is gained from independently exploring and manipulating the environment. Sources of reinforcement, in the form of rewards, grades, privileges, and recognition are a stimulus for motivation.

A sense of accomplishment also involves the ability to work alongside, or to compete with, others. Cooperation, as well as the skills of negotiation, are important skills to be learned. Involvement with peers is critical to this accomplishment.

Physically, children aged seven to eleven should experience slow, steady growth in height and weight, not marked by dramatic growth spurts. From a psychoanalytic point, this is the time of latency. Latency occurs as a period of sexual tranquility between the Oedipal phase of early childhood and the erotocism of adolescence (Whaley and Wong, 1989).

When assessing the perception children have of the occurrence of hassles in their environment, it is necessary that they understand the concept and be able to communicate that hassles have occurred. The intellectual development of children age seven to eleven facilitates accurate understanding and communication. Also, the relative calm in this age group, without stormy physical and emotional changes, helps ensure more consistent responses on the part of children.

Families For the purposes of this study, family refers to a single parent or married couple and their natural and adopted children who live in the same household. AS a generic term, family encompasses a multiplicity of meanings. In the American Heritage Dictionary (Morris, 1982), a family is described as "the most instinctive, fundamental social or mating group in man and animal, but especially the union of man and woman through marriage, and their offspring; parents and their children" (p. 474). Morris' definition makes reference to the traditional nuclear family, ie. a husband, wife, and their children (natural and adopted) who live in the same household. Variations in the family include extended families, consisting of two or more families related by blood or marriage, and single parent families, which result either from divorce, or the recent trend for single individuals to adopt children (Miller, 1980). In order to limit the number of variables, the author is confining the definition of family to traditional two-parent, or single parent families.

Assumptions of the Conceptual Framework

1. Hassles are a daily occurrence.
2. Hassles are energy depleting to the child with CF.
3. The diagnosis of CF and its treatment are accompanied by stress.
4. Children age seven through eleven are capable of honestly and accurately reporting on the incidence and impact of stressors, as are their parents and siblings.
5. The Swachman-Kulczycki rating score is an accurate indicator of the health status of children with CF.
6. Families are open systems, capable of exchanging energy, information, and matter with the environment and with each other.
7. The experiences of all family members will have an impact on each individual family member.

Limitations

1. Confounding of dependent and independent variables. The scale currently in use to measure hassles (Kanner, Coyne, Schaefer, and Lazarus, 1980) contains some items that are reactions to stressors (ie. the experience of fear, concerns, worries, conflict) rather than environmental inputs that are independent of the reaction or state of mind of the individual. Thus,

dependent and independent variables may blend, in a circular kind of causality.

2. Appropriateness of hassles categories. The original hassles scale (Kanner et al., 1980) does not itemize hassles that are appropriate to children's experiences. Barnes, Peek, and Spence (1988) have devised a modified children's hassles scale, but this data collection tool has had limited usage.
3. Limitations in data collection. There is currently no means of collecting data on the occurrence and impact of hassles on infants, toddlers, and pre-schoolers. Thus, data collected on hassles in studies based on the proposed conceptual framework may not truly represent families with children of these ages.
4. Factors other than hassles may impact on the physical health of children with CF, and are beyond the scope of the proposed framework.
5. Presently, there is no way to truly obtain measures of family hassles.

Summary

In chapter one, the author has provided an introduction to the question of the relationship of hassles to health status of children with CF. Rationale was given for using CF as a prototype of chronic illness in children, definitions were developed, and the relevance of the question to nursing practice was explored. Chapter II will contain a review and critique of research literature pertinent to this project. In Chapter III, a conceptual framework to guide the study of the relationship of family hassles to the health of children with CF will be developed. Chapter IV will focus on a discussion of the implications of the concept of hassles to the CNS in primary care. Imogene King's theory for nursing (1981) will be used to explain the role of the clinical nurse specialist in facilitating the adaptation of families with children with CF to the everyday hassles they encounter.

CHAPTER II

LITERATURE REVIEW

Overview

In this chapter, literature pertinent to the development of a conceptual model to study the relationship between the health status of school-age children with CF and the hassles reported by these children and their famililes will be reviewed and critiqued. Two major bodies of literature will be analyzed. The first is literature related to childhood chronic illness and its impact on affected children, siblings, parents, and the family as a whole. The second body of literature is that which deals with the relationship of stressors and illness.

Impact of Childhood Chronic Illness on Families, Parents, Siblings, and Affected Children

Impact on the Family

Two early studies (Meyerowitz and Kaplan, 1967; Tropauer, Franz, and Dilgard, 1970) which investigated the relationship between CF and family functioning will first be cited because they gave initial direction to research in the area of childhood chronic illness and are considered classics. Meyerowitz and Kaplan (1967) studied 111 families of children with CF and explored the effects of CF on the personalities of family members, intrafamilial role functioning, and family-community relationships. Data were gathered from parents of CF children by personal interview by staff members from a major CF center. All hypothesized relationships between variables reported were statistically significant at the 0.05 level or beyond.

The findings of the Meyerowitz-Kaplan (1967) study are very comprehensive, and not all of the results relate to the proposed conceptual model. Some of their findings which are relevant include the fact that 96% of parents surveyed reported that family routines were very difficult since the diagnosis of CF, resulting in major change in family functioning. Secondly, parental feelings of distress were related to the children's activity outside the home. Parents of children who engaged in outside activities and sports, and were attending school, were significantly more likely to display psychophysiological manifestations of stress than parents of children not thus engaged. Finally, parents in families consisting of one CF child and more than one normal child reported better adaptation in family functioning with less disruption than parents in families with only a CF child, or a CF child and one normal sibling. Although these findings are old, they have not been disputed in more recent literature.

Two major limitations of the Meyerowitz-Kaplan (1967) study emerge as salient. First, their study families were intact two-parent families only, perhaps not truly relevant in current society's trend toward single-parent and reconstituted families (Miller, 1980). Secondly, the authors obtained responses from parents only, making the assumption that they were representative of familial responses. These criticisms point out the need for updated studies which include non-traditional families, and which elicit responses from family members other than just parents.

Strengths of the Meyerowitz-Kaplan (1967) study are that the number of families included was large (n=111), families were viewed from both systems and developmental perspectives, and results of the study suggested multiple areas of further research in understanding the impact of chronic illness on family functioning. Even in modern research, the Meyerowitz-Kaplan (1967) study is frequently cited as the basis for new investigation.

The second major early study of family functioning and chronic illness was that of Tropauer, Franz, and Dilgard (1970). Cognizant of the fact that improved life expectancy for children with CF brings with it the need for ongoing family adjustment and adaptation, Tropauer et al. (1970) conducted psychological studies of 200 children with CF and their mothers. Data were elicited from these mothers and CF children only; data about remaining family members were collected from the mothers only. Their findings, reported in an anecdotal and speculative fashion, suggested that CF imposed considerable emotional impact on the child and his family, especially when family members were unable to communicate with and support each other. The small number (n=20) may not be representative of families with CF children. The primary outcome of the Tropauer et al. study was to suggest areas of future research, rather than report analytically sound findings.

More recently, Venters (1981) observed that the majority of family stress literature overlooked exploration of family dynamics in families faced with a long-term and continuous stressor, such as CF. Little focus had been placed on identifying the ability of families to maintain and/or develop functional, ongoing behavioral patterns to meet present and anticipated future illness-related hardships. In an attempt to fill this gap in the literature, Venters (1981) conducted a study to examine the typical course of familial adaptation to the chronic stress of CF, and to determine how the behaviors of families who demonstrated adequate long-term family functioning differed from behaviors employed by those families who experienced difficulty with family functioning over time.

Venter's (1981) study included 100 families who were currently managing 129 children with CF. One time interviews were conducted with parents who brought their children to a major CF research and treatment center. Responses were not elicited from the children themselves. Using the Adequacy of Family Functioning Scale, the 100 study families were categorized into high, medium, or low levels of family functioning. Having established these three levels of functioning, the interview data were then searched for the most salient concepts which would suggest group commonalities of response to CF from the time of diagnosis until data was being collected, as well as differences concerning functional and dysfunctional family responses to CF. Characteristics of high level functioning families were found to be the ability to give meaning to the illness, and the sharing of the burdens of CF, not only with the family, but with outside help, as well. Conversely, low level functioning families were generally unable to give meaning to the illness, and were unable share the burden with the family, or with outside sources.

Venters (1981) acknowledges certain limitations of the data obtained in her study. For example, self-report data relies upon obtaining information about familial behavior over time through recall, and can be inaccurate due to perceptual biases. In addition, since the study population was not a random sample of all CF families, but most of the complete population which visited the clinic during the study period, generalizability of the findings extends only to the participants. Venters (1981) did not provide documentation about the reliability and validity of the Adequacy of Family Functioning Scale, leaving the reader uncertain about how representative the findings were.

Cowen, Corey, Keenan, Simmons, Arndt, and Levison (1985) conducted a study to determine family adaptation and psychosocial adjustment to CF in pre-school children. Data were obtained one time, with no longitudinal follow up. Parents of 51 pre-schoolers with CF completed Problem Inventory, Pre-school Behavior, and Family Assessment scales. These measures solicited (a) parents' perception of child-related problems; (b) the component processes of family functioning; and (c) the behavior of the pre-school child. Parents of a control group of 31 healthy pre-school children completed the same questionaires. The reader will note that this is the first study cited so far which utilized a control group.

Cowen et al. (1985) describe the validity of the Pre-school Behavior questionnaire as high, with the scale differentiating normal children from those with psychological disturbance ($P<0.0001$), and replication as good, with a mean inter-rater reliability of 0.79. The Family Assessment Measure, while undergoing refinement at the time of the writing, showed test-retest reliability of 0.93 for adults and 0.94 for children. The Problem Inventory scale was a checklist designed to assess parents' views of ten child-related difficulties their family has had to face, and no standardization of norms were available.

Surprisingly, parents of healthy pre-schoolers reported more child-related problems than did parents of CF children ($P<0.001$). Perhaps this is because parents who must confront the severity of CF go on to minimize the normal stress of this developmental period. Also, unexpectedly, it was shown in this study that there was no significant difference in family functioning between the study and control groups. Problems in family functioning which were reported--extra demands on time, life centered around the child, and need to constantly watch the child--were remarkably similar in both the study and control groups. Speculatively, this latter finding may be related to the fact that pre-school age children with CF are often not seriously ill during this early stage of their disease. Additionally, all children in the study had been diagnosed with CF for at least one year, possibly giving families opportunity to adjust. Overall, the findings of the Cowen et al (1985) study contradict earlier investigations of family life with chronic childhood illness which conclude that the experience is largely negative (McCollum and Gibson, 1970; Mattson, 1972).

Aside from the lack of standardization of one of the data collection tools in the Cowen et al. (1985) study, a limitation of the study was the lack of a longitudinal perspective for the exploration of psychological and physical states during the pre-school period. One-time data collection prevented a description of parent-child interaction over time, and especially across periods of illness exacerbations.

Stullenbarger, Norris, Edgil, and Prosser (1987) used questionnaires to obtain a one-time sample of CF mothers' perceptions about actual and ideal parenting styles, CF related daily problems, and competence behavior their children displayed while exploring the environment. Earlier studies had suggested that children with chronic illness may experience difficulty adapting to their environment, secondary to maladaptive family behaviors (Gayton and Friedman, 1973; and Pless and Roughman, 1971), but this finding was not supported by Venters (1981) or Cowen et el. (1985). Criteria for entry into the study included being the primary caregiver of the CF child, age of the

CF child being 1-4 years, and bringing the child for care to the pulmonary clinic conducting the study (n=26). The three data collection tools were the Problem Areas Checklist (r=.68), Childhood Personality Scale (r=.92), Parents' Report of Ideal Parenting Style (r=.67), and Parents' Report of Actual Parenting Style (r=.85). Pearson product moment coefficients were computed to determine the relationship between any two variables. ,Study findings indicated that problems reported by mothers did not contribute significantly as a predictor variable for competence scores. The mothers' ideal parenting style was the best child competence score predictor, perhaps because mothers were more like the ideal parent they described than the real parent they perceived themselves to be. Probably the most important finding of the Stullenbarger et al. (1987) study is that mothers of CF children did not report child competence scores or actual parenting scores below the median, suggesting effective adjustment and adaptation to CF. Limitations of the Stullenbarger et al. (1987) study include a small number of subjects (26), lack of randomization and control groups, no longitudinal collection of data, and eliciting parental responses from mothers only.

This concludes the literature review on research related to the effects of chronic illness on the family. In these studies, many methodological problems exist, including the lack of randomization, small numbers of subjects, and lack of control groups. The most glaring limitation to these studies has been the assumption by the authors that responses obtained from either one or both parents truly reflects the impact experienced by the family when a member has a chronic illness. Future family research in this area must attempt to get at the impact of chronic illness on all members, in order to intervene to facilitate successful adaptation.

<u>Effects on Parents</u> Very little research was found related to the effects of chronic illness on parents specifically. Most of the early work in this area was done when the child was mentally retarded (Faber, 1959; Olshansky, 1962; Weisbren, 1980) or had physical structural defects (Barsch, 1968; Gardner, 1969). Four studies were found, however, that were relevant to the effects of childhood chronic illness on parents and will be discussed in this section.

McCubbin, McCubbin, Patterson, Cauble, Wilson, and Warwick (1983) wondered if there are coping patterns parents use to manage family life and health successfully when a child member has a chronic illness, and if these coping patterns have any effect on the health of the child. Data were collected on 100 families who had a child with CF, using the Coping Health Inventory for Parents (CHIP). This instrument was developed by McCubbin, McCubbin and Cauble in 1979. It is an 80-item checklist providing self-report information about how parents perceive their overall response to the management of family life with a CF child. Coping behaviors, such as "believing that my child(ren) will get better" or "talking with the medical staff when we visit the medical center" are listed. Parents record how helpful (0 to

3) the coping items are to them in managing the illness situation. Responses fall into three major coping patterns: 1) maintaining family integration, cooperation and an optimistic definition of the situation; 2) maintaining social support, self-esteem and psychological stability; and 3) understanding the medical situation through communication with other parents and consultation with the medical staff. Using Chronbach's alpha, reliabilities of .79, .79, and .71 have been computed for the three coping categories respectively. In addition to parental coping behaviors, data were compiled on the CF childrens' health status, using the indices of height, weight, and pulmonary functioning.

After analyzing their data, McCubbin et al. (1983) concluded that fathers' coping behaviors were primarily associated with the system maintenance dimensions of family life, promoting family structure, activities, and planning while maintaining family organization with rules and procedures. Mothers' coping behaviors, on the other hand, were focused on the interpersonal dimensions of family life--family cohesiveness and family expressiveness--encouraging members to be concerned, helpful and supportive of each other and to act openly and to express their feelings directly.

When considered with the child's health status, positive coping by both father and mother was associated with improvements in all three health indices of height, weight, and pulmonary functioning. These findings lend support to the proposed conceptual framework presented in this paper, in which the author proposes that family functioning in response to hassles affects the health of children with CF. The findings also suggest that parental coping is a viable target for primary intervention, and that strengthening of coping efforts can positively impact CF children's health status.

The McCubbin et al. (1983) study appears to be methodologically sound for the most part. The authors concede that the use of a single sample of families without the benefit of cross-validation poses some limitations in generalizability. But it does add to the body of knowledge regarding childhood chronic illness because it focuses not on the hardships these families face, but on what parents do to try to actively cope with the situation.

The second study in this section was conducted by Powers, Gaudet, and Powers (1986), and also was concerned with assessing the coping patterns parents utilize when a child has a chronic illness. Powers et al. used the same data collection tool as did McCubbin et al. (1983) (CHIP), but were primarily interested in determining if the independent variables of sex or ethnicity (Anglo-American, Hispanic-American, Native American Indian, Asian American, and black) altered coping reponses. Health of the child was not looked at, and the chronic illnesses experienced were not identified.

Subjects of the Powers et al. (1986) study were 107 parents representing 65 families who belonged to a support organization for parents of chronically ill children. Self-report data were obtained at one time. Analysis of the data showed that mothers overall scored strengthening the self and comprehending the medical situation as more helpful coping responses than did fathers. When Anglo-Americans and Hispanics were compared, Anglo-Americans scored strengthening the self by getting away from home tasks and becoming more involved in social activities as being more helpful in coping than did Hispanics. This finding reflects sexual and cultural differences which must be considered when one is helping families develop effective coping with childhood chronic illness.

Walker, Ford, and Donald (1987) were interested in finding out if the independent variables of age and severity of illness (CF) were correlated with maternal stress levels. The sample consisted of 32 mothers of children with CF and 32 mothers of healthy children. Age groups (4-5 yrs., 8-9 yrs., 11-14 yrs., and 15-19 yrs.) were fairly well matched in both populations. Illness severity, as assessed by Shwachman ratings (see Chapter I of this paper for a discussion of this instrument), were derived on all CF children. The sample mothers responded to The Center for Epidemiological Studies Depression Scale, the Parenting Sense of Competence Scale (Girbaud-Wallston, 1977), and The Questionaire on Resources and Stress (Holroyd, 1974). They also described, in an anecdotal fashion, two incidents of misbehavior by the child. They then reported their response to the incident by choosing from a series of bipolar items which evaluated strictness, appropriateness, and effectiveness of their discipline.

In analyzing their data, Walker et al. (1987) found that mothers of preschoolers and early adolescents with CF were significantly more depressed than mothers of healthy children in those age groups ($p<0.01$). Mothers of children with CF did not perceive themselves to be under significantly more stress than mothers of healthy children in the areas of child dependency and management difficulty, limits on family opportunity, family disharmony and financial stress. In the early adolescent age group, mothers of CF children showed a slight tendency to feel more burdened in their caretaking role than mothers of healthy children ($p<0,01$),

Overall, mothers of healthy and CF children did not differ in perceptions of their parenting competencies. However, a significant interaction effect for child health status by age group ($p<0.05$) indicated that in the middle childhood years, mothers of children with CF rated themselves as significantly more competent than did mothers of healthy children in the same age group. Analysis of mothers' responses to child misbehavior were rated as equally strict, appropriate, and effective by both groups. There was no significant effect of child age on the discipline ratings for either group.

No information was supplied about reliability and validity of instruments used in the Walker et al. (1987) study. Randomization was not used, so it is not known if responses are truly representative of CF mothers. The stratification into four age groups meant that there were only eight children in each group, a rather small number from which to draw generalizations. The study results do reflect the probability that there are some funtions of age of CF children which influence maternal functioning, related to normative changes of childhood development. This study is important, too, because it supports the idea that families of children with CF are capable of potential adaptation, rather than being overwhelmingly dysfunctional.

The final work to be evaluated in this section is that of Gibson (1988). Gibson's study was one of very few in the topic area which were found in the nursing literature. Using Lazarus' and Folkman's theory on stress and coping as a framework, Gibson sought to find out what coping behaviors parents used in dealing with the stressors associated with raising a child with CF. Information was obtained by having parents complete a series of open-ended and closed-ended questionnaires as they waited at the clinic for their scheduled CF child visit.

After data were obtained, coping responses were divided into the three main categories of social support, problem-solving skills, and a system of beliefs. Social support was the resource identified as most helpful by the majority of parents. Unfortunately, the nature of the social support was not identified in this study. Family was identified as the most important provider of social support. Two other important support systems which were identified by parents were the CF clinic staff, and CF parents support group. Problem-solving skills which were identified as helpful were those that allowed parents to focus on the positive aspects of their situation. Parents tried to identify positive attributes of both the family and the CF child. Statements, such as "There is lots of love in our family", and "He brings us so much happiness and love" were cited as examples.

The Gibson (1988) study is fraught with methodological inadequacies. There was no randomization of subject selection. Filling out a questionnaire in a busy waiting room is hardly conducive to data collection, particularly when open-ended responses were elicited. The instrument used was not really described, and no data were provided regarding reliability and validity. In discussing her analysis of the data, Gibson (1988) wrote in general terms only, and there is no indication of statistical procedures or significance levels used. For these reasons, much caution would need to be exercised when applying Gibson's research findings to practice.

This completes the discussion of studies related to the effects of childhood chronic illness on the parents of these children. It is apparent that there is a lack of work in this area, especially when one considers the prevalance of chronic illness in children. Overall, the four studies cited had many methodological weaknesses. Only one of the investigators used a control group (Walker et al, 1987), so application of findings to the population are limited. No author used randomization to select subjects, and it is a widely known phenomenon that individuals who choose to participate in a study may be different from those who choose not to participate. Data collection tools and statistical testing techniques were not well described in two of the studies (Gibson, 1988; Powers et al, 1986). Data has usually been collected from the mother only, but the findings were reported as parental findings, making the assumption that fathers necessarily agreed with the responses. It is clear that future researchers need to conduct studies using designs which remedy these shortcomings if we are to truly understand how parents deal with childhood chronic illness.

Effects on Siblings Siblings of children with chronic illness have long been considered a population at risk for maladjustment and maladaptive behaviors. Indeed, much of the early work done in this area appeared to bear out these findings (Binger, Ablin, Feuerstein, Kusher, Zoger, and Mikkelsen, 1969; Crain, Sussman, and Weil, 1966; Turk, 1964; Wold and Townes, 1969). Most of the early studies on siblings were performed without benefit of comparison groups. This, coupled with the fact that, for many chronic illnesses, life expectancy has been prolonged in the last few years owing to new advances in treatment, shows the need to look at more recent work in an attempt to determine how siblings fare with childhood chronic illness.

In reviewing literature published within the last ten years related to the effects of childhood chronic illness on siblings, few research articles were found. By contrast, several articles were found that discussed application of the little research that was found. This is somewhat surprising in view of the trend in health care to consider not only the sick child, but also the whole family, in planning interventions designed to facilitate adaptation to childhood chronic illness.

The first study to be considered is one which was conducted by Lavigne and Ryan (1979), who were interested in determining the psychological adjustment of siblings of children with chronic illness or handicaps. Data were collected on 203 children who were either siblings of ill children (n=157) or siblings of well children (control group; n=46). These authors sought to expand the existing data base by broadening the number of disease or handicap groups whose effects on siblings have been studied. Sick children fell into three major categories of hematological conditions, cardiac problems, and conditions requiring plastic surgery. Children in the first two groups are generally considered to have chronic conditions which impair functional capacity, but their impairment is not highly visible. The hematology group, however, was made up primarily of patients with leukemia and solid tumors, illnesses which are more likely to be fatal within a limited time than cardiac conditions. The children who required plastic surgery to correct their defects have a highly visible problem, which was thought to have a more negative social stimulus (Lavigne and Ryan, 1979). Children in all groups ranged in age from three to thirteen years, and an attempt was made to match ages of the control and study groups.

All data in this study were obtained from parents; there was no sibling participation. The Louisville Behavior Checklist (LBCL), which is a standardized, 164-item questionnaire, was used to collect information on parental perceptions of their well childrens' psychological adjustment. There was no indication of the reliability or validity of the LBCL, other than the statement that it is standardized. Parents of ill children were approached in the waiting room as they waited for their child's clinic visit and asked to participate in the study. Parents of healthy, control children were contacted by mail and asked to rate siblings of a child who was a pupil at school (and who was named on the form), using the same LBCL.

After analyzing their data, Lavigne and Ryan concluded that, considered collectively, siblings of children with chronic illnesses do seem more likely to experience adjustment or behavioral problems than siblings of healthy children, and they do appear to be at risk for certain problems at certain ages. Siblings of all three illness groups were significantly more withdrawn and irritable than siblings of well children. There was a significant trend toward greater pathology in male siblings compared to female. No main effect of birth order on psychologic adjustment was demonstrated. Instead, this study found significant interaction effect of birth order and sex on psychologic adjustment: among siblings younger than the disabled child, female siblings were worse off than male, whereas the reverse was true in older siblings. Finally, Lavigne and Ryan found no evidence that severity of disability, presumably an important determinant of the time parents spend caring for the disabled child, has a relationship with siblings' psychologic problems. All findings reported were significant at the 0.05 level, with many findings exceeding this level.

There are important limitations to the Lavigne-Ryan study. As in criticism of an earlier study in this paper, collecting data from parents as they await a clinic visit is not optimum. The LBCL is lengthy (164-item), and takes considerable time to complete. The two different methods of data collection (mail versus direct contact) may have influenced the study outcome. Finally, data collection allowed for no sibling input, and relied entirely upon parental perceptions of their adjustment to the chronic illness in a brother or sister.

The second study of sibling response to childhood chronic illness was conducted by Breslau, Weitzman, and Messenger (1981). This was a comprehensive study of healthy siblings of 239 children with a variety of chronic illnesses who received care at two major tertiary medical centers in Cleveland. Findings were compared with those of a control group of children. Data collection tools were the Psychiatric Screening Inventory, the Level of Disability Scale, and Perceived Effect on Siblings Scale. Reliability for these data collection tools was given as .57, .88, and .75 respectively. To collect the data, mothers were interviewed in their homes for two to three hours with a structured questionnaire, portions of which were self-administered during the interview.

The findings of the Breslau et al. (1981) study were computed at a significance level of 0.01 or better, and are summarized as follows: (1) Siblings of disabled children did not manifest higher rates of severe psychological impairment or greater overall symptomatology when compared to control subjects. (2) Siblings of disabled children scored significantly higher on measures of interpersonal aggression with peers and within the school setting. (3) The type and severity of disability bore no relationship to the psychologic functioning of the siblings. (4) Sex and age were not related to psychologic functioning nor was birth order. However, birth order was found to have a statistically significant interactive effect with sex. Among siblings younger than the disabled children, male siblings had greater impairment than female siblings, and the reverse was true for siblings older than the disabled children. This latter finding is the opposite of that reported by Lavigne and Ryan (1979). Overall, however, on the total inventory, siblings of chronically ill children were more similar to the control group than they were different, lending further credence to the idea that families are generally able to cope with the stressors imposed when a child has a chronic illness.

The third and last research related to sibling response to childhood chronic illness was conducted by Sourkes (1987). This paper is considered qualitative research because it examines the experience of siblings who live with a child with a life-threatening illness, and the adaptive means they mobilize to negotiate this unique life stress. From her work as a psychotherapist, Sourkes presents case vignettes which illustrate themes she sees as related to siblings. The areas that Sourkes explores are causation of illness, visibility of the illness and the treatment process, identificatin of the illness, guilt and shame, sibling relationships with parents, academic and social functioning, and somatic reactions. Sourkes concludes that siblings often hold two views about the cause of the patient's illness. One view stems from the medical information which they have heard from their parents and the doctors. The other is their own "private" version, often unarticulated, but to which they cling with tenacity, even though it may be fraught with emotional and cognitive confusion.

The visibility of the disease/treatment is important to siblings. The siblings' task is to coordinate the concepts of constancy and change. They must learn that it is the same person who looks so different, or that despite constancy in appearance, inner change is making the child ill.

The fear of contracting the illness runs high in siblings, because they see so many similarities among themselves and the patient. This is especially relevant when the siblings cannot stipulate a true cause for the illness. Guilt and shame, either for having escaped the illness, or arising from the misconception that they somehow caused the disease to occur in their brother or sister, are common feelings among siblings. Guilt can also be stirred up from another source: their sense of shame at having a child in the family who is "different", either in appearance or in functional capacity.

A pervasive complaint of siblings which was reported by Sourkes (1987) was the diminished attention from their parents, especially during periods of hospitalization of the sick child. When the patient was home, the siblings' complaints shifted from that of "too little attention" to "preferential treatment of the patient". It is important for siblings to be able to express these feelings, and for the parents to respond.

The siblings' concern with the patient's illness were seen to often affect two areas of daily functioning: school and peer relationships. Children reported being unable to concentrate in school, and peer relationships were often curtailed for a variety of reasons. Some children turned their focus to achieving in school, in order to assure a sense of competence in the face of stress and helplessness.

Finally, Sourkes (1987) reported an increase in somatic reactions in the siblings she studied. Weight loss or gain, enuresis, accident proneness, and physical symptoms (Sourkes did not specify which physical symptoms were reported) were seen to be the result of living with a child with a life-threatening illness. According to the author, helping siblings to understand the psychological meaning behind the somatic concerns may relieve them of the necessity for psychosomatic expression.

Sourkes' data are useful in that they illustrated concepts which other authors have discussed when studying sibling response to childhood chronic illness. But exactly how significant these concerns are in the whole sibling population is impossible to assess from her work. As a psychotherapist, Sourkes was dealing with children who may already have been identified as having adjustment problems. The sick children in her study all had leukemia, which often has a different course than CF and other chronic illnesses. Areas requiring further study using rigorous research techniques, are suggested by Sourkes, however, and her work is important in that respect.

This concludes research literature related to the effects of childhood chronic illness on siblings. Studies in this area are very sparse indeed. The Breslau et al. (1981) work was the most comprehensive (n=239), and the most methodologically sound, including a control group. But their study did not elicit any data from the siblings themselves, a rather curious phenomenon when sibling adjustment was the focus of their investigation. Because the conceptual model proposed in this paper is based on family systems theory, it is important that responses of all family members be included.

Impact on the sick children In reviewing the literature related to the impact of childhood chronic illness on the ill children themselves, more research was found than in the previous focus areas of this chapter. Although the emphasis in this section will be on literature published within the last ten years, a classic study, conducted in 1970 (Tropauer, Franz, and Dilgard) will be presented first because their method of data collection allowed for the expression on any and all concerns about CF by sick children and their mothers. This provided future researchers with a wealth of information about areas of children's adjustment and adaptation to chronic illness which needed further investigation.

The purpose of the Tropauer et al (1970) study was to describe attitudes, feelings, and reactions experienced by a representative group of children with CF and their families. Twenty children with CF and their mothers were selected for the study on the basis of their availability for psychiatric and psychological examination. There was no randomization, and data regarding "family response" were collected from mothers only. Children ranged in age from five to twenty years. Mothers were questioned about their child's personal and social adjustment, reactions to the medical routine, and apparent anxieties. Their own feelings, worries, thoughts about prognosis, and major frustrations were discussed. Reactions of siblings were explored, in addition to marital adjustment, family closeness and the ability to communicate about the illness.

Children were asked about their experiences in relation to the illness. Their understanding of the nature and prognosis of CF, their hopes and expectations, and predominant fears in relation to the disease were explored. In addition, children were administered a modified form of the House-Tree-Person tool, a commonly used source of information about the possibility of psychological conflict. Children are asked to draw 1) a picture of a house, 2) a picture of a tree, 3) a picture of a person, and 4) a picture of a person of the opposite sex. Data were not provided about the reliability and validity of the House-Tree-Person tool.

Findings of the Tropauer et al (1970) study are reported in a primarily descriptive, anecdotal manner, without specific statistical analysis, so it is not possible to ascertain the exact impact of CF on the children. The authors do come to the following conclusions, however. First, the experience of CF has considerable emotional impact on the child and his family. The absence of obvious signs or complaints of emotional distress concurrent with organic disease does not exclude the possibility that such distress exists. Secondly, an intellectual understanding of the disease achieved through educational efforts does not necessarily eliminate psychological complications, but efforts to educate the child helps produce a relationship which may prove beneficial during later emotional crises. Third, the less communicative and less emotionally supportive members of the family are with each other, the more likely that difficulties in adjustment to the illness will arise. Fourth, parents who are under stress themselves are sometimes capable of intensifying the child's difficulties or remaining unaware of his problems in adjustment. This finding points out the need to include responses of the children, rather than just those of the parent(s). Finally, the primary anxieties and conflicts related to cystic fibrosis vary according to age. Adolescence was noted to be a particulary trying time because the treatment necessary for the disease enforces a dependancy upon children at a time when independence is a primary concern.

The Tropauer et al (1970) study is important because it was one of the few found which included responses elicited from children themselves. There were methodological weaknesses, however, such as lack of randomization, lack of a control group, and incomplete reporting of statistical analysis, if any, was done by the researchers.

Drotar, Doershuk, Stern, Boat, Boyer, and Matthews (1981) compared the adjustment of children with CF (n=91) as rated by parents and teachers to that of physically healthy siblings (n=71), other physically healthy children (n=61), and other chronically ill children (n=47). Questionnaires were mailed to parents of all children with CF, aged three to thirteen years, who received care at a large medical center, and parents of the remaining three groups of children. No information was given as to how these latter groups of children were selected. Parents who chose to participate completed the Louisville Behavior Checklist (LBCL) which lists 120 statements of 120 deviant behaviors to be scored by the parent. The LBCL has been standardized on a large population of children in the United States, and discriminates children whose symptoms warrant psychiatric referral from normally functioning children. Teachers of these same children filled out the School Behavior Checklist (SBCL), which includes 96 statements of deviant behaviors. The SBCL has also been standardized on a large population of U.S. children.

In computing statistical analysis of their data, Drotar et al (1981) chose a conservative significance level of 0.01. They concluded that children with CF achieve an age-adequate level of adjustment at home and school. Adjustment was largely unrelated to severity of illness. As a group, children with chronic illness had slightly less adequate adjustment as rated by parents. Severe adjustment problems, however, were rarely reported.

The Drotar et al. (1981) study used data collection tools that were reliable and valid. They utilized a control group, and the number of children studied was sufficiently large. As a limitation, these authors did not elicit responses from the children themselves, instead relying upon the perceptions of parents and teachers to be accurate.

Lewis and Khaw (1982) examined family functioning as a mediating variable affecting adjustment in children with CF. Three groups of children with CF (n=31), asthma (n=26), and a healthy control group (n=27) were randomly selected from a large childrens' medical center in Boston and a school system in the same area (healthy children). The three groups were matched for age (seven to twelve years), and gender. The tests administered were the Family Adaptability and Cohesiveness Evaluation (FACES), Behavior Problem Checklist (BPL), and the Piers-Harris Children's Self-Concept Scale. Reliability and validity had not yet been reported for FACES. The BPL and Piers-Harris tools had reported test-retest reliabililty of 0.82 and 0.72 respectively. FACES and BPL were completed by parents, and the Piers-Harris tool was completed by the children themselves.

Among the three groups of children, Lewis and Khaw (1982) found no significant difference in family functioning or children's self-concept. The two groups of chronically ill children did have significantly higher frequencies of behavior problems than the healthy children ($p<0.01$). But when there was statistical control for effects related to family functioning in the areas of cohesion and adaptability, this difference was not statistically significant. These authors concluded that children with chronic illness adjust in basically healthy ways and that any deficits result more from mediating factors, such as family functioning, than from the presence of the disease per se.

The Lewis and Khaw (1982) study is one of the most methodologically sound found by this author in the review of relevant literature. Subjects were randomly selected, data collection was consistent across groups, and groups were controlled for age, an important factor when studying a disease such as CF which is progressively deteriorating in nature. Their data were subject to rigorous statistical analysis. Probably the major limitation of the Lewis and Khaw (1982) study was that there was not any control for socio-economic status, a factor which could contaminate their findings.

Stein and Jessop (1984) assessed the relationship between the health status of 219 children with chronic illness and their psychological adjustment. Measurement of psychological adjustment was accomplished using the Personal Adjustment and Role Skills Scale (PARS) which contains subscales on six dimensions described in the literature as being associated with patterns of maladjustment in children. Reliablity of the PARS was reportedly 0.82. The form was completed by a parent. The second variable, health status, was measured using the criteria of days in bed or absent from school in the last two weeks, and days and numbers of hospitalizations in the last six months. Additionally, functional status was assesed by evaluating the child's capacity to perform age-appropriate roles and tasks.

In analyzing their data, Stein and Jessop (1984) correlated each measurement of health status, i.e. days absent from school in the last two weeks, or number of hospitalizations in the last six months, with the chid's PARS score. Their data provided evidence that, in general, adjustment among chronically ill children is relatively independent of degree of illness, as measured in this study. Both functional status and days absent from school are associated with poor psychological adjustment ($p<0.01$). Which is cause and which is effect is unclear. In the sample, family composition altered the correlation between each of the morbidity measures and psychological adjustment. The association was strongest when the mother and child were living with an adult other than the child's father (in most cases, a grandmother or other female relative). It is not known if this finding is related to lack of a male figure in the child's life or not. The association between health status and psychological adjustment was weakest when both parents were living together with the child. The situation when the mother is alone with the child is an intermediate one varying with sickness measures. These findings suggest that the relationship between morbidity status and psychological adjustment is less for children living with both parents than for those living with a mother and another female adult.

The sample used in the Stein-Jessop study was predominantly poor, and was drawn from a minority population. Thus, the findings are not generalizable to the general population without further replication studies. The authors concede that their findings do not shed light on the issue of cause and effect in the relationship betwen psychological adjustment and health status. A cause and effect relationship can only be determined through longitudinal studies that provide more careful control of variables.

The final study on the effects of chronic illness on children to be discussed is one completed by Simmons, Corey, Cowen, Keenan, Robertson, and Levison, 1987). The primary question to be answered in their work was how well latency-age children (six to eleven years) cope with CF, as reflected by their behavior. The population of the Simmons et al. study included all families seen in a major CF clinic whose CF child was latency age and who agreed to participate. The number of participating families was 56 families of male children and 52 families of female children with CF (total n=108). Packets of questionnaires were distributed to participating families at the time of a regular clinic visit, with instructions to complete them at home and return them by mail. Four data collection tools were used in the Simmons et al. study: the Piers-Harris Children's Self-Concept Scale, the Children's Health Locus of Control (CHCL), the Child Behavior Checklist (CBCL), and the Family Assessment Measure (FAM). All four measures are self-report tools, with the first two being completed by latency age CF children and siblings, and the latter two being completed by their parents. Additionally, physical parameters for the children with CF were derived from clinic charts, and they included pulmonary function status, height and and weight, and amount of hospitalization during the last three years.

In analyzing their data, Simmons et al. first looked at demographic and health status data of non-participants and determined there was no statistical difference between the groups. This was necessary to rule out possible contamination effects if families who agreed to participate were found to be different from those who refused. Next, correlation coefficients for all psychosocial and physical variables were calculated, followed by a students' t-test to determine the statistical significance of correlations and differences in the group means.

The CF children had a higher rate of behavioral adjustment problems than the general population (23% vs 12%). This prevalence of behaviors was not related to disease severity, however. Behavioral problems identified were largely of a somatizing nature, rather than conduct disturbances. Somatic complaints were more common in CF males than females (48% vs 25%), but were not related to severity of illness. The authors suggest that the tendancy toward internalizing behaviors, as manifested in somatic complaints, show that these children with a potentially fatal disorder do worry about the disease and its effects, even though they do not act out on it.

Although behavior scores indicate some pathology, other psychosocial scores showed strengths in both the CF children and their non-CF siblings. The self-concept scores are increased in all groups and are significantly higher than the published norms for the Piers-Harris scale ($p<0.01$). On the Children's Health Locus of Control, CF children have elevated scores, showing that they perceive themselves to have greater control over their own health compared to the published norms for healthy children (Healthy siblings did not complete the CHLC). Overall, the children in the Simmons et al. (1987) study showed that they are able to function adequately, but they do show the effects of the stress of chronic illness by showing more behavior disorders, particularly of a somatizing nature, and especially among males.

The Simmons et al. study is cross-sectional, so is not able to show the effects of CF on latency age children over time, or with exacerbations of the disease. Other than that, their study design was fairly sound. Data were elicited from both children and parents, and the data collection tools have long been established to have good reliability and validity. Statistical analysis was stringent. The findings of the Simmons et al. (1987) are useful because they concur with those of Steinhausen and Schindler (1981) who reported similar behavior disturbances in children and adolescents with CF.

Summary of Childhood Chronic Illness Literature

This completes the review of research literature related to the impact that chronic illness has on children. The major limitation of this body of research is that no studies were found which were longitudinal in nature. Thus, the effects which occur over time, and especially during an exacerbation of the illness, are not assessed. Randomization of subjects was used in only one study (Lewis and Khaw, 1982). Three researchers used control groups (Drotar et al., 1981; Lewis and Khaw, 1982: Simmons et al., 1987). Only two studies included responses from the children themselves (Lewis and Khaw, 1982; Simmons et al., 1987). Further studies must be designed which address these limitations, in order to truly assess the impact of chronic illness on school age children, and the relationship of life stressors to health status.

The following section of this paper will contain a review and critique of literature pertinent to the relationship between stress and health. Research articles will be presented, with an analysis of their methodology and application potential.

Stress and Illness

It has long been postulated that stimuli (e.g. life events) associated with emotinal arousal cause changes in physiological processes (Cannon, 1929). In both retrospective and prospective investigations, modest but statistically significant relationships have been found between mounting life change and the occurrence of such incidents as sudden cardiac death, myocardial infarction, accidents, athletic injuries, leukemia, several immune-related disorders, diabetes, and streptococcal infection (Bramwell, Masuda, Wagner, and Holmes, 1975; Kobasa, Maddi, and Kahn, 1982; Locke, 1982; Murphy and Brown, 1980; Rahe, 1972; Rahe, Bennett, and Romo, 1972).

Over the years, various life event measures have evolved into widely accepted instruments used in the investigation of the relationship between life stress and physical illness. The most common measure was developed in 1967 by Holmes and Rahe. Their Social Readjustment Rating Scale (SRRS) is a list of 43 events deemed to require substantial change. Individuals recall whether these events happened to them in the last six months. Items are weighted, and after completion of the checklist, a cumulative score is obtained. The score is then used to explain negative changes in one's health status.

Holmes and Rahe's Social Readjustment Rating Scale (SRRS) has received extensive criticism of its assumptions (Kaplan, 1979; Mechanic, 1974), and scale construction (Rabkin and Struening, 1976). Because it is subject to recall of past events, there is the chance of forgetting events, or having their perceptual significance blunted. The SRRS taps discrete changes, and does not measure ongoing stressful conditions. Reports of reliability and validity are very inconsistent. Despite this criticism,the SRRS continues to be a dominant data collection tool in the area of behavioral medicine (Kanner, Coyne, Schaefer, and Lazarus, 1980).

In contrast to the major life events stance taken by Holmes and Rahe (1967), Lazarus and his colleagues have proposed the immense adaptational significance of the relatively minor stressors that characterize everyday life (Kanner et al, 1980). These relatively minor stressors are labeled "hassles" and are defined as the irritating, frustrating, distressing demands that to some degree characterize everyday transactions with the environment. Because hassles are chronic, and may build up over time, these authors have proposed that assessing hassles would be a better indicator of health outcome than major life events are. Pursuing this proposition, Kanner et al. developed a scale which focused on relatively minor events, namely, the hassles and uplifts of daily life. The Hassles Scale consists of a list of 117 hassles that was generated from the areas of work, health, family, friends, the environment, practical considerations, and chance occurrences as guidelines (Kanner et al, 1980). The Uplifts Scale, drawn from the same areas as hassles, consists of 135 uplifts. Respondents were asked to indicate which of the hassles and uplifts occurred to them in the last month, how frequently they happened, and what their intensity was (1 to 3). Additionally, respondents completed a major life events questionnaire at the beginning of, and ten months into, the study period to determine which of these major events had occurred. Psychological well-being was measured using the Hopkins Symptom Checklist and the Blackburn Morale Scale. The study lasted for 10 months, after which data were analyzed to determine if hassles and uplifts scores correctly predicted psychological well-being.

Kanner et al. (1980) found that hassles are more strongly associated with adaptational outcomes than are life events. Further, hassles contribute to symptoms independent of major life events. Regarding uplifts, Kanner et al. found that for women only, uplifts are positively related to life events. Although this study only began the task of studying hassles and their possible relationship to health, it was the first systematic attempt to determine if such a relationship existed.

The relative effectiveness of hassles and uplifts and of major life events in predicting concurrent and subsequent somatic symptoms was examined in a longitudinal study conducted by DeLongis, Coyne, Dakof, Folkman, and Lazarus (1982). One hundred subjects, ranging in age from 45 to 64 years, completed the hassles and uplifts scale, developed by these authors, once each month for nine consecutive months. Hassles and uplifts were rated for both frequency and intensity (1 to 3). One month prior to the start of the study, these same subjects completed a major life events scale, including events that had occurred during the previous 2 1/2 years. A self-report of health status, including indexes of overall health, a somatic symptoms score, and an energy level score was completed both at the start and completion of the study.

DeLongis et al (1982) computed correlations between hassles, uplifts, life events, and the health questionnaire. High levels of hassles were associated with both initial health status (r= -.21) and final health status (r= -.33), as well as with initial (r= .27) and final (r= .35) somatic symptomatology. Hassles were found to be more strongly related to somatic health than were major life events, and uplifts did not contribute to the variance in health outcomes.

A major limitation to the DeLongis et al. (1982) study is the reliance on memory for accurate reporting of life events. The 2 1/2 year time of recall may mean that data collected was not truly accurate. As events fade into the distant past, they may be perceived as being less important than those experienced more recently. A second limitation occurs because it is not known if self-report of symptoms is an accurate indicator of health. More research needs to be conducted to determine whether this is a valid means of health measurement.

In attempting to shed additional light on the proposed relationship of hassles and uplifts to health, Monroe (1982) studied 73 volunteer employees from a moderate sized corporation. Participants completed the Psychiatric Epidemiology Research Interview Life Events Scale to identify life events they experienced during the previous twelve months,the General Health Questionnaire to assess psychological symptoms, and an untested scale measuring uplifts and hassles. The study lasted four months, with subjects completing the General Health Questionnaire, and hassles and uplifts scales on a monthly basis. In compiling his data, Monroe computed means for hassles frequencies, uplifts frequencies, and the psychological test scores.

Two major findings emerged from Monroe's (1982) study. First, daily hassles are a significant predictor of psychological symptoms, and, secondly, daily hassles appear to be better predictors of psychological symptoms than life events. No significant correlations were found between uplifts frequency and major life event categories. All findings were reported at the 0.01 significance level. Monroe's findings confirm those of Kanner et al. (1980).

Further studies of the relationship of hassles and health were conducted by Burks and Martin (1985) and Jandorf, Deblinger, Neale, and Stone (1987). Although the methodology differed, both studies were concerned with the idea that ongoing stress was more important than discrete major life events in predicting changes in health status. Data collection was similar to that described in the previous research in this section (e.g. self-report). The results of both studies support earlier findings that undesirable daily events have more predictive power than major life events in predicting health.

Despite the criticisms that have been voiced about the use of various forms of major life events scales, more studies relating major events to physical symptomatology were found in the recent literature than those relating daily, on-going stressors to the same variable of health. Because of their preponderance in the literature, several of these studies will be cited briefly at this time.

Sarason, Sarason, Potter, and Antoni (1985) assessed the effects of both social support and life events on illness. Their subjects were 163 men enrolled in the Basic Enlisted Submarine School. Life changes during the past year were evaluated for incidence and severity, using the Life Experiences survey, a modification of the Holmes and Rahe (1967) life event rating scale. A self-report health questionnaire elicited data about the occurrance of symptoms in the last year (e.g. ringing in ears, nausea, rashes). Illnesses were also tabulated, using school medical records. No data were supplied about the reliability or validity of the data collection tools.

Correlations among the variables of life events, social support, and health status were conducted. Findings support the idea that negative, but not positive, life changes are associated with illness report. Of particular interest is the fact that negative events occurring during the preceeding 7-12 months were not correlated with medically diagnosable illnesses during that period, but were instead correlated with illnesses in the succeeding time period. This finding is consistent with growing evidence associating time lags between stressors with various types of illness manifestation.

Several limitations are noted in the Sarason et al. (1985) study. No data were supplied regarding reliabililty and validity of the data collection tools. Subjects were asked to report fairly mild symptoms that occurred in the past year. Accurate recall of the incidence and accurate timing of these minor symptoms seems fairly unrealistic. Randomization was not a concern because the entire student population at the submarine school participated, but this means the research findings are applicable only to other submarine school students.

In a study reported in the nursing literature, Yarcheski and Mahon (1986) investigated the relationship between perceived stress and symptom patterns in 136 seventh and eighth grade children. Fifty-two percent of the subjects were female and 48% were males. Participation was not randomly assigned. The researchers visited the seventh and eighth grades in the target school, and explained the purpose and procedures of the study to the students. Both student and parental consent were obtained for study participation. The study students completed, while at school, the Modified Adolescent Life Change Events Questionnaire, The Jalowiec Coping Scale, the PRQ-Part 2, which measures perceived social support, and the Symptom Pattern Scale to measure psychological, physical, and psychosomatic manifestations of psychological distress. The symptom patterns are experienced as psychological inertia, free-floating anxiety, physical bodily complaints, and somatization of distress. Yarcheski and Mahon (1968) were careful to establish reliability for the data collection tools they used in this study. In order, the tools had reliabilities of .75, .80, .86, and .77.

In the Yarcheski and Mahon (1986) study, the relationship between perceived stress and symptom patterns was upheld (p=0.02). Affective oriented coping was also positively associated with symptom patterns (p=0.007). For example, the more that these children used coping strategies such as day-dreaming, crying, and worrying, the more they experienced manifestations of distress. Yarcheski and Mahon suggest that health care providers should discourage young adolescents from using emotion-focused coping strategies, teaching them instead to use concrete coping methods.

Perceived stress was strongly and positively related to symptom patterns under the condition of low social support (.55). Conversely when social support was perceived to be high, the relationship between perceived stress and symptom patterns decreased and was not statistically significant (.33). The implications of this finding are that health care providers need to identify the diverse sources of support for adolescents in an attempt to improve adolescent well-being.

The Yarcheski and Mahon (1986) study was fairly well designed. Selection of subjects was not randomized, but randomizing from the already small population would have shrunk the size of the subject cohort. Data collection tools were described, and data were provided for their reliability. Stringent statistical analysis was applied, and the findings were reported in detail. From a nursing perspective, the Yarcheski and Mahon (1986) study was significant because the authors discussed implication for nursing practice thoroughly.

Smith, Gad, and O'Grady studied 26 children with CF aged twelve to eighteen years of age to determine if there was a relationship among psychosocial functioning, life change, and clinical status in adolescents with cystic fibrosis. Self-esteem, perceived social support, and locus of control were all measured, using self-report measures. Additionally, a measure of life change for adolescents was administered, with subjects indicating which of 46 selected life events he or she had experienced within the past year. Items on the measure are very similar to those found on the original Holmes and Rahe (1967) measure of life events. Data were also collected from a normative adolescent population (n=97) on the number of life events experienced in the last year. No other data were collected from these healthy adolescents. The variables of self-esteem, perceived social support, locus of control and life events were correlated with health status in CF, which was determined by using both pulmonary and general measures (no further information was given), and with each other.

Smith et al. found no significant difference in the number of life events experienced by CF and normal adolescents. However, "sicker" CF adolescents reported significantly more negative events in the past year than the "healthier" CF adolescents. If this is so, the less sick adolescents with CF reported fewer negative events in the past year than the healthy children. This finding is curious, and requires more investigation by researchers interested in finding out how adolescents cope with the stressors of CF. There was no significant difference between groups in the number of positive events which were reported.

CF subjects had a lower self-esteem (30th %ile) than normal adolescents, but were above average on general adjustment (90th %ile), suggesting satisfactory adaptation to the illness. Locus of control scores showed a relatively external orientation, with the CF adolescents perceiving themselves as being less capable of exerting control over environmental events.

The majority of the CF adolescents were functioning at the appropriate grade level for age and over 80% expressed an active interest in planning for the future. These results in general support those of others who have found that most adolescents with CF appear to proceed through adolescent development in a functional manner.

The findings reported by Smith et al (1983) must be evaluated cautiously. A major concern is the small number of subjects (n=26). Another problem is the authors' use of recall of life events of the distant past (one year). Finally, data regarding statistical soundness of the data collection tools has not been supplied, and this limits the assumptions one may make about study results.

In the Western Journal of Nursing Research, Van Os, Clark, Turner, and Herbst (1985) reported on their study testing the relationships between stressful life experiences of the primary caretaker and various measures of the severity of the CF child's illness. One hundred one families who received care for their CF child at a large CF center participated in the study. Most CF children were in the preschool or elementary age groups. After agreeing to participate, the primary caregivers of these children filled out a demographic questionnaire, the SRRS (Holmes and Rahe, 1967) to measure life events, and the Cystic Fibrosis Child Health Summary, which is a brief questionnaire designed to ascertain information regarding recent hospitalizations and antibiotic therapy. In completing the SRRS, caregivers reported incidence of events only, and not their perceived severity. Swachman scores were determined for each CF child by the director of the center. The Swachman score provides an index of the severity of CF based on an assessment of activity level, physical status, nutritional status, and chest X-rays.

Using Pearson product-moment correlations, Van Os et al. (1985) found that life events scores were reliably associated with current antibiotic therapy in the CF children they studied ($r=.212$, $p=<0.025$). The authors never stated so, but it is assumed that they associated antibiotic therapy with an exacerbation of the child's condition. This needs to be clarified for the reader, because it is not uncommon for children with CF to receive antibiotics on a prophylactic basis, not related to their present condition (Whaley and Wong, 1989). Further analysis showed that four life events were correlated with 17.9% of the variability of current antibiotic therapy. In declining order of importance, these events are marital separation, vacation, a loan of less than $10,000, and divorce. Three additional life events accounted for 12.7% of the variability of the ratings of chest X-rays (part of the Swachman rating). The three events are a child leaving home, gaining a new family member, and a change in work responsibilities. Van Os et al. (1985) note that of the seven life events named, four are changes in family membership, and the remaining three may represent financial stress. They suggest that it would be prudent for nurses to pay particular attention to the occurrence of these life events in CF families, because of their potential for adversely affecting the health of the children.

Several limitations are seen in the Van Os et al.(1985) study. The sample was not controlled for age, and results were not stratified, so it is unknown if all age children respond according to the data results. The life events score was based on recall of the past, and the shortcomings of this sort of data collection have been discussed earlier in this section. Longitudinal studies would be more accurate. There was no control for time of diagnosis. Obviously, analysis of data would be different when a child was just diagnosed than if the diagnosis had been made a year or more ago, allowing the caregiver time to adjust.

The final research on the impact of life events on the health of chronically ill children which will be reported here is that of Patterson and McCubbin (1983). These researchers thought that the impact of a single stressor on a family could best be understood if other life changes being experienced simultaneously were taken into account. Their hypothesis was that a pile-up of life changes in a family in a six month period is associated with changes in the health status of a chronically ill member.

To assess pile-up, Patterson and McCubbin (1983) developed the FILE (Family Inventory of Life Events). The selection of items to be included was guided by those life changes appearing on other individual life change inventories (i.e. Coddington, 1972; Dohrenwend, Krasnoff, Askenasy, and Dohrenwend, 1978; Holmes and Rahe, 1967). In addition, situational and developmental changes experienced by families at different stages of the life cycle were included, because of the change they require in families. Responders indicate 1) whether the change was anticipated or not, 2) the amount of adjustment (0 to 8) required by the family to cope with the change, and 3) whether this adjustment continues or is completed. No data were supplied regarding reliability and validity.

Subjects in the Patterson and McCubbin (1983) study were 100 families of one or more children with CF who received care at a major CF clinic. All clinic families were invited to participate, so random selection was not used. The majority (93%) of families had one child with CF; the remainder had two CF children at home. Ages of the children ranged from three months to twenty eight years.

Parents in participating families were sent the FILE questionnaire, and asked to record family life events and changes experienced by the family during each six month period of the past year. In two-parent families, parents were asked to collaborate in filling out the form. Indices of child health (height/weight and pulmonary functioning) were obtained from two clinic visits approximately three to four months apart.

Using Pearson product moment correlation, Patterson and McCubbin (1983) found that a pile-up of life changes in a family in a six month period is associated with changes in the health status of a chronically ill member. Four categories of life changes plus total life changes were analyzed. Changes related to family relationships (r= -.19, p<0.05), family management and decisions (r= -.28, p=<0.01), family and health (r= -.24, p=<0.05) , and family finances (r= -.26, p=<0.01) were significantly correlated with overall pulmonary functioning. No significant correlations were found between the height/weight index of child health and family life changes.

It might be argued that life change events are actually caused by decline in health status, rather than the other way around. Indeed, when one studies the conceptual model which has been presented in chapter II of this paper, it is evident from the feedback loop that cause and effect are bi-directional to a certain extent. Perhaps some of this question could be answered by designing a study that measures health status at the onset, collects data regarding life events (FILE) in an ongoing fashion, then re-measures health status at the mid-point of the study, and at some time after the six month period(s) of data collections.

There are other limitations to the Patterson and McCubbin (1985) study. The wide age range of children (3 months to 28 years), without stratification, makes it difficult to make application of the findings. Data were elicited from parents only, with the assumption that such data represented family findings. This has been a consistent weakness in research purporting to measure family responses to childhood chronic illness. The data collection tool was new, and no data were supplied regarding its reliability and validity.

Finally, data collection for life events was conducted in a retrospective manner, making the responses subject to error.

Summary of Stress and Illness Literature

This concludes the review and critique of the literature related to the relationship between stress and illness. At this point in time, there are two major schools of thought regarding the best way to understand the relationship between the two concepts. Major life events, as discrete occurrances which require varying amounts of change, are thought by some researchers to adequately explain changes in health. Other researchers, realizing that no family deals with only one stressor at any given time, are more interested in studying the additive effects of stressors, both minor annoyances (hassles) and major happenings (crises) to explain changes in health. The latter stance is the one taken by the author of this paper. More studies in this area are needed. Methodological issues must be addressed. Longitudinal data collection, inclusion of responses from all family members, stratification of children being studies into age groups, and better use of control groups are issues which demand attention in future studies.

In the fourth and final chapter of this paper, King's theory for nursing will be presented as a framework for nursing practice in caring for families of children with cystic fibrosis. Implications for nurses in research, education, and practice will be discussed.

CHAPTER III

CONCEPTUAL FRAMEWORK

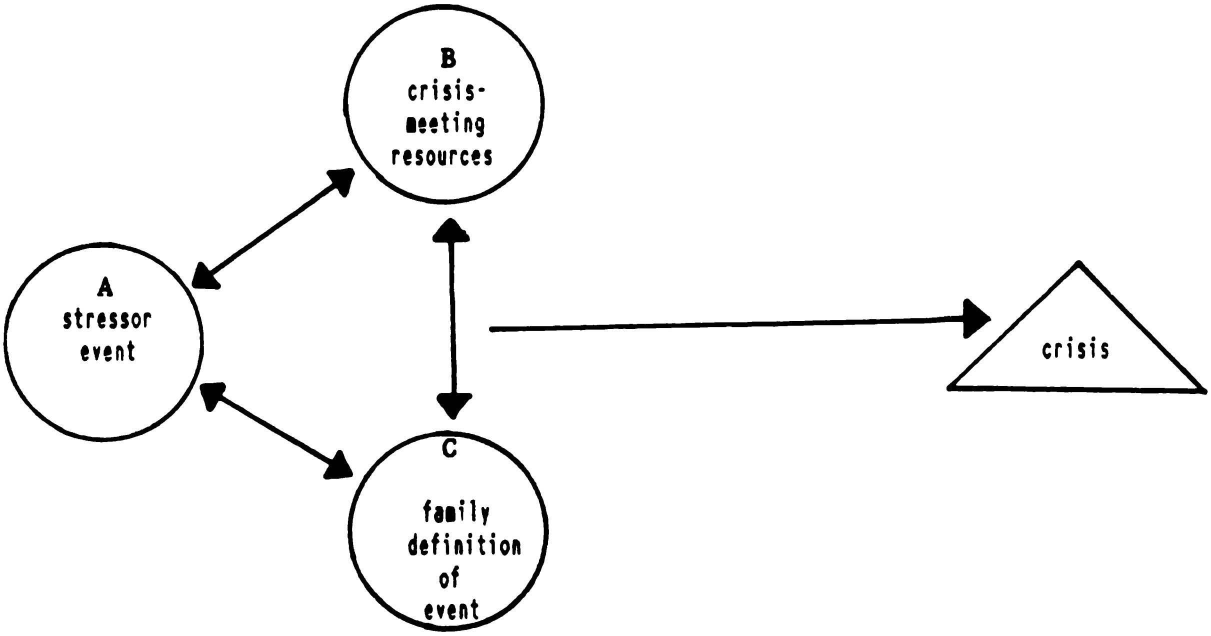
Introduction

Having reviewed the literature related to the concepts of chronic illness in children and the effects of family stressors on the health of these children, it now becomes important to organize these concepts into a framework. A conceptual framework provides practitioners with a context in which they can describe, explain, and predict human responses to states of disequilibrium. Further, this same framework allows for the prescription of interventions to facilitate human adaptation to disequilibrium (Chinn and Jacobs, 1983). Conceptual frameworks, then, provide for structure and consistency in nursing study and practice.

The Hill ABCX Family Crisis Model

The earliest conceptual foundation for research to examine the variability of individuals' responses to stressors has been the Hill (1949, 1958 A) ABCX model. The Hill model was used primarily to study the variability of individual responses to separation and reunion during war, and is depicted on the following page.

A critical idea in the ABCX model is that A (the event) is influenced by several phenomena. Hill (1958 B) postulated that no crisis-producing event is the same for any given family, and that its impact may vary according to the several hardships that might accompany it. In other words, what might be construed as a crisis-precipitating event under one set of circumstances might be construed as much less serious under different circumstances.



A (the stressor event)--interacting with B (the family's crisis-meeting resources)--interacting with C (the definition the family makes of the event)--produces X (the crisis). The second and third determinants--the family resources and definition of the event--lie within the family itself and must be seen in terms of the family's structures and values. The hardships of the event, which go to make up the first determinant, lie outside the family, and are an attribute of the event itself.

Figure 1 (Modified from Hill, 1958 B)

It is important to understand Hill's (1949) definition of crisis at this point. Hill stated that crisis is "any sharp or decisive change for which old patterns are inadequate" (p. 51). Patterns refer to modalities of family functioning, and Hill's definition implies that new patterns of functioning need to be developed if families are to deal successfully with crises. Examples of new patterns of functioning might include reallocation of roles of family members, or requesting help from outside the family (McCubbin and Figley, 1983).

Obviously, Hill's ABCX model is primarily crisis oriented, and is not helpful in explaining what happens if events are not viewed as crisis-producing. Human experience, alone, leads one to know that individuals are continually appraising events/non-events, the majority of which can be handled with existing patterns of functioning.

In an attempt to explain individual and group differences in the degree and kind of reaction produced by certain environmental demands and pressures, Lazarus and Folkman (1984) describe a process they call cognitive appraisal of events. Using their taxonomy, events are appraised as 1) irrelevant, 2) benign-positive, or 3) stressful. When an encounter with the environment (event) carries no implication for the well-being of the individual, it is placed in the category of irrelevant. It impinges on no value, need, or commitment of the individual, and requires no mobilization for action (p. 32).

Benign-positive appraisals of encounters occur if the outcome is perceived as positive. That is, it preserves or enhances well-being, or promises to do so (Lazarus and Folkman, 1984, p. 32). Benign-positive appraisals are accompanied by pleasurable emotions, such as joy, love, happiness, exhilaration, or peacefulness.

Stress appraisals include harm/loss, threat, and challenge (Lazarus and Folkman, 1984, p. 33). In harm/loss, an individual experiences some damage to self, such as injury or illness, damage to self- or social-esteem, or loss of a valued person or object. Threat concerns harms or losses which have not yet occurred, but which loom on the horizon. Challenge has much in common with threat, in that they both call for mobilization of efforts at dealing with potential events. The main difference is that challenge appraisals focus on potential for growth and gain, whereas threat appraisals center on potential harms.

In summary, it is through cognitive appraisal that individuals assess the meaning of events/non-events in their lives. This meaning may be different for two persons who are faced with the same circumstance under comparable conditions. Similarly, a given individual may appraise an identical event/non-event differently at various times of occurrence in his/her life. Cognitive appraisal determines how much change the individual thinks he must make in response to the event/non-event which is being confronted. Some events/non-events require no change, others require minor change (hassles), and still others, which are appraised as crises, require major change in functioning.

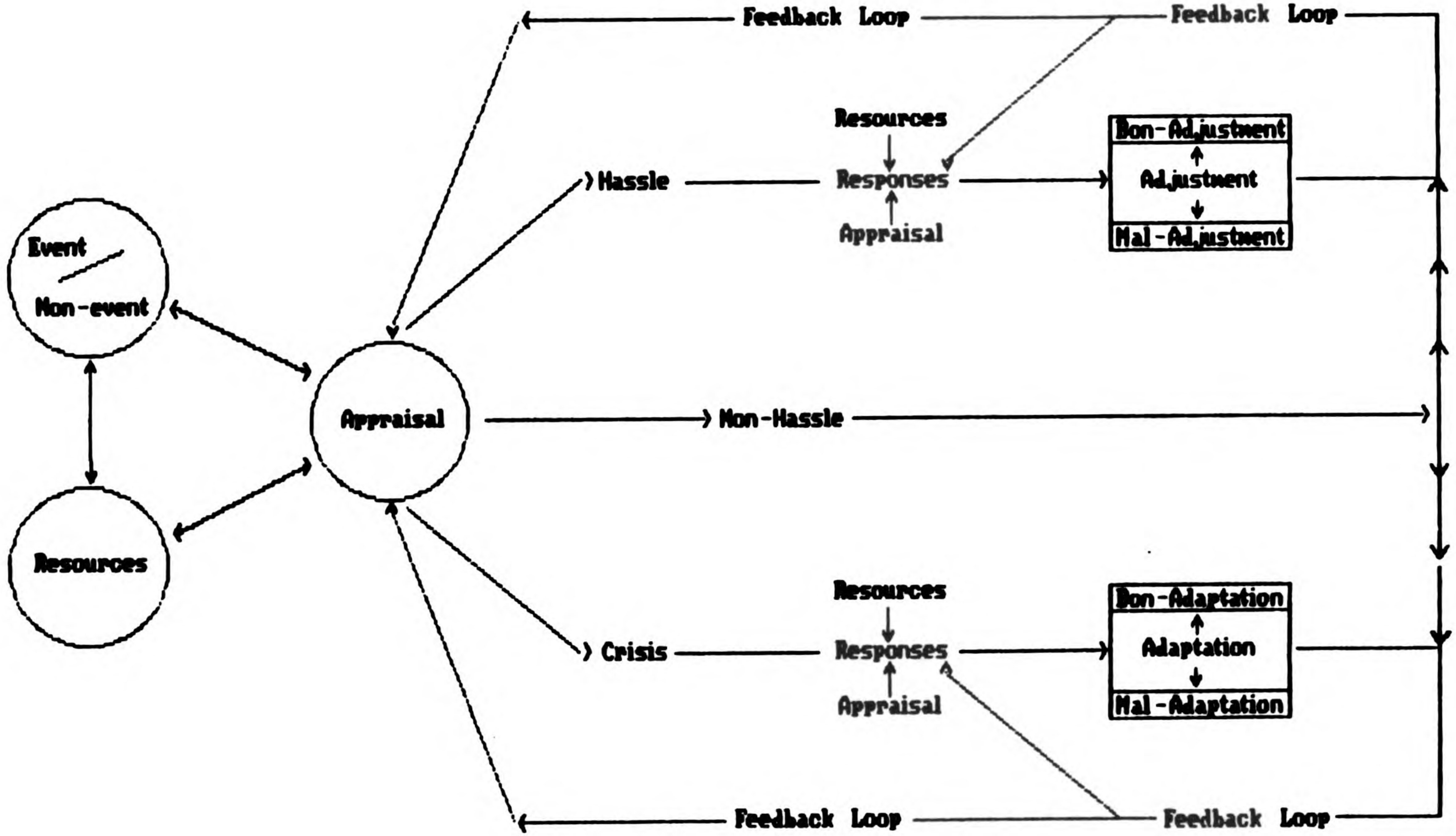


Figure 2: The processes of Adjustment and Adaptation.

Adaptation of the ABCX Family Crisis Model

In developing a conceptual model to study the effect of family stressors on the health of children with CF, one must take into account the cognitive appraisal process of assigning events as crises, or as less serious events. Further, the conceptual model must explain what happens, once an assignment is made. Are non-crises responded to differently than crises? Is the outcome different? How does the outcome of any given encounter with an event influence other encounters which are occurring simultaneously, or in the future?

The conceptual model which this author has developed to study the effect of family stressors on the health of children with CF is depicted in Figure 2 of this paper. It is at once evident that the model is an adaptation of Hill's (1949, 1958 A) ABCX family crisis model. The X (crisis) factor has been changed to explain how this phenomenon varies, allowing for events to be appraised as crises, hassles, or non-hassles; i.e. from requiring major changes in family functioning to requiring little or no change at all. Responses are shown to be a key factor in how events/non-events are appraised and acted upon. Responses to hassles can lead to bon-adjustment or maladjustment, and efforts to manage crises can lead to bon-adaptation or maladaptation. Regardless of whether the outcome is positive or negative, however, feedback from all encounters is shown in the model to influence appraisals of, and responses to, all future encounters. A detailed discussion of the concepts in the proposed model follows.

Definition of Concepts in the Model

Event or Non-Event The first variable to be discussed is the event/non-event. At this early stage in the conceptual model, a simple dictionary definition will suffice. In The American College Dictionary (1982), the word event is defined as "an occurrance, incident, or experience" (p. 454). A non-event, by contrast, would be the lack of an occurrance, incident, or experience. These occurrances, incidents, or experiences, or lack thereof, refer to interactions individuals have with the environment, both internal and external (Folkman and Lazarus, 1984). Obviously, events can vary from small and mundane (i.e. setting out pancreatic enzymes for a CF child each morning) to those of great significance, requiring much change (i.e. the death of the CF child). Similarly, non-events may be seemingly insignificant (i.e. missing a single CPT treatment) to major (i.e. not being eligible for state assistance for CF related hospitalizations). But because the classification of events as minor or major has a large subjective, or perceptual component, events or non-events at this stage in the conceptual model are largely devoid of any inherent weighting of severity.

In the proposed conceptual model, events/non-events lead to some change in function. Obviously, when one is driving, coming upon a stop sign calls for bringing the vehicle to a halt, which is a change in function. But this is an ongoing and expected part of driving, and does not call for extra or unusual responses. In this case, stopping for the stop sign is not a stressor event. Having a child run in front of the car would also call for a stopping of the vehicle. In the latter example, however, the stop is unexpected, and any rational driver would appraise the event as being much more serious than the first.

Families who include a child with CF in their membership are continuously faced with events/non-events that they must appraise. For example, it is common for children with CF to cough quite profusely following their regular chest physiotherapy as they attempt to expectorate the thick mucus that has been loosened. Because it is expected and on-going, this coughing does not alarm the family. But if that child's school teacher reports a dramatic increase of productive coughing in the classroom, or if hemoptysis occurs with it, the child's cough is appraised to be much more serious, perhaps heralding a decline in health, and requiring changes in the families usual mode of functioning. The child must be seen by a physician, and hospitalization may be the outcome.

Since events/non-events call for some change, they can be viewed in a stress framework (Selye, 1957). According to Selye, the human body attempts to maintain homeostasis, and any upset in the steady state of the body calls for re-adjustment. When events/non-events are relatively minor, homeostasis is easily maintained , using a repertoire of responses which have previously been incorporated into ones' usual pattern of functioning. But if changes are excessive in either quantity or quality, they tax the capacity for readjustment, thereby producing stress.

In Selye's writings, events/non-events are viewed as noxious, a concept argued by recent researchers (Dohrenwend and Dohrenwend, 1981; Zautra, Guarnaccia, and Dohrenwend, 1986). A more current view is that humans are seen as reactive to stimuli (stimulus-response psychology), and stimuli (events/non-events) are commonly thought of as events impinging upon the person, as well as conditions arising from within the person (McCubbin and Figley, 1983).

Resources In the proposed conceptual model, events/non-events are ultimately defined as non-hassles, hassles, and crises. It is necessary to consider the resources that are available to meet the demands of the event/non-event when making an assignment into any of these categories. Burr (1973) defines resources as the family's ability to prevent an event of change in the family social system from creating a crisis or disruptiveness in the system. Hill (1958) very succinctly described resources to be the adequacy-inadequacy of family organization. McCubbin and Thompson (1987) expand on these two definitions when they equate resources with family strengths, and call them the "family's capabilities for resisting crisis and promoting family adjustment" (p. 6).

Understandably, as families grow and develop, the events/non-events which have the most impact on their function will change in significance. According to McCubbin and Thompson (1987), families with school-age children face the hardships of intra-family strains, work-family strains and the difficulties associated with them. The critical family resources identified by these authors are:

> "Family accord about their competency
> Qualitative marital communication
> Shared orientation to child rearing
> Satisfaction with family life
> Financial management skills
> Shared couple orientation to relatives and friends
> Satisfaction with quality of life" (p. 8)

The McCubbin-Thompson (1987) discussion of family strengths has arisen primarily from a family development framework (Duvall, 1977), which allows for anticipation of family changes due to developmental, and thus, fairly predictable, events. But the experiences of a family, when a school-age child has CF, are much more complex, and the normative, developmental changes are complicated by the non-normative changes brought about by the disease process. From this standpoint, it is helpful to consider family systems theory (Hazzard, 1971) when determining family strengths that will serve as resources.

From a systems perspective, a family can be viewed as a highly interactive unit, designed to facilitate growth and development of its members (Hazzard, 1971). A healthy family system promotes individual autonomy among its members, while maintaining a strong sense of emotional cohesion. Although it maintains its established power structure and role relationships, the healthy family has the flexibility to modify its rules adaptively in response to specific situational (non-normative) or developmental (normative) stressors. Thus. a healthy family is a dynamic system that responds to internal and external stressors while maintaining its equilibrium.

Two major concepts emerge as salient to a discussion of family resources from a family systems viewpoint. The first of these concepts is boundaries, which are rules specifying who can participate in the family, and how much input or exit of energy, information, and matter will be allowed within the family (Miller, 1980). When a school-age child has CF, boundaries must be permeable enough to allow for the input of information and assistance from outside the family system when responding to the major stressors which accompany the disease.

The second family systems concept which influences resources is role. If a family has adopted a traditional outlook, where father is breadwinner, and wife is homemaker and mother, the entry of a child with CF into the family may call for role changes. The husband may have to assume caregiving roles to assure that the affected child receives required chest physiotherapy. The mother may need to work outside the home to cover extra expenses incurred as a result of the disease and its treatment. Even siblings may need to assume some care-giving or home maintenance duties not previously a part of their roles. The ability of family members to change or modify their roles serves as a critical resource in dealing with events/non-events (Miller, 1980).

No one would dispute the fact that the above stated family strengths are valuable resources. But as described, they cite primarily attitudes and skills, which are learned over time. If one is to take into account a holistic view of resources, a more immediate and concurrent view must also be undertaken (Thomas, 1987). Variables of time, money, and energy need to be seen as impacting positively upon the family's ability to prevent an event/non-event from creating a crisis within the system. Cystic fibrosis imposes a drain upon all three of these resources--time, money, and energy--as families attempt to deal with the disease and its associated hardships.

Another resource is the help families receive from the social environment (Thomas, 1987). Examples might be home-bound teachers for children too ill to participate in a regular school experience, or household and child care assistance from a local church group. On a more subtle note, support from the environment may take the form of approval from society for the way in which a particular family deals with the stressors associated with CF.

From the preceeding discussion, it can be seen that resources arise from within and from without the family. Some resources are the result of attributes of the family and its members, while others are results of characteristics of the stressor event itself.

Appraisal The third concept to be discussed is appraisal. Early in this chapter, appraisal was defined as a cognitive process, whereby a particular encounter with the environment is evaluated as relevant to one's well-being (Lazarus and Folkman, 1984). In primary appraisal, an individual evaluates whether he or she has anything at stake in the encounter. In secondary appraisal, an evaluation is made as to what, if anything, can be done to overcome harm or to improve the probability of benefit (Folkman, Lazarus, Dunkel-Schetter, DeLongis, and Gruen, 1986). Various options exist, including altering the situation, accepting it, seeking more information, or holding back from acting impulsively and in a counter-productive way (Folkman et al, 1986, p. 992). Primary and secondary appraisals merge as individuals determine whether the person-environment interaction is regarded as significant to well-being, and if so, whether it is primarily threatening, leading to harm and loss, or primarily challenging, leading to mastery or benefit. It must be remembered that both threatening (negative) and challenging (positive) appraisals can produce stress in individuals and families. The resulting stress does not reside in the particulat event/non-event or within the individual. Instead, stress arises from the interaction between the individual and the situation (Miller, 1981).

In the primary appraisal process, threat and challenge are not necessarily mutually exclusive (Lazarus and Folkman, 1984). The prospect of a child going to CF summer camp is likely to be appraised as having the potential for gaining new friendships, physical skills, and self-esteem. At the same time, the experience entails the risk of a relapse in the child's condition, or the emergence of a sense of independence, which would run counter to already established family role relationships.

Just as threat and challenge can occur simultaneously, appraisals can shift as encounters or experiences unfold. Early successful efforts at dealing with a threat or loss encounter may result in increased self-confidence, allowing individuals and families to change their initial appraisal to one of challenge. Similarly, challenge appraisals can quickly turn to threat appraisals if efforts to manage an interaction with the environment--internal or external--do not produce the anticipated outcome. Keeping up with peers in a physical education activity may be initially appraised as a challenge by a school age child with CF, who has experienced previous success in certain athletic activities, and who remembers the warm glow of peer admiration. But if shortness of breath and bouts of coughing stop his efforts short, the challenge quickly becomes a threat as the child anticipates loss of peer approval, and is reminded of the serious, ultimately fatal, nature of the disease.

When individuals determine that something must be done about a situation, whether a threat or a challenge, a further form of appraisal is salient. The evaluation of what might be done is called secondary appraisal (Lazarus and Folkman, 1984). "Secondary appraisal activity is a crucial feature of every stressful encounter, because the outcome depends on what, if anything, can be done, as well as on what is at stake" (p. 35). This complex process takes into account what response options are available, the likelihood that a given response will accomplish what it is supposed to, and the likelihood that one can be effective in employing a certain response.

Bandura's (1982) writings shed some additional light on the concept of secondary appraisal. In his writing, Bandura discussed outcome expectancy as one's belief that a given response will lead to a certain outcome. Efficacy outcome refers to the understanding that one can be successful in carrying out the behavior necessary to produce the desired outcome--that one has power over outcome. Individuals and families who are convinced they can master stressful encounters through their own action are less likely to be threatened, or to feel helpless or hopeless (Clark, Rosenstock, Hassan, Evans, Wasilewski, Feldman, and Mellins, 1987; Gibson, 1988).

Rolland (1987) proposes a classification schema of chronic illness which is helpful in understanding how individuals and families appraise the stressors associated with these illnesses. The course of the illness is an important variable, and Rolland classifies diseases like cystic fibrosis as having a relapsing or episodic course. A distinguishing feature of this disease course is the alternation of stable periods of varying length with periods of flare-up or exacerbation (p. 205). Strain on the family system occurs as a result of both the frequency of transitions between remissions and exacerbations, and the ongoing uncertainty of when a recurrance will occur. Mishel (1981, 1988) pioneered research on the effect of uncertainty of illness, and demonstrated that uncertainty hampers the cognitive appraisal process, at both the primary and secondary levels. Uncertainty occurs in a situation in which an individual is unable to assign definite meaning or value to objects or events and/or is unable to predict outcomes (Mishel, 1988). If a threat cannot be labeled, it is not possible to identify responses which might successfully be employed to deal with that threat. Uncertainty has been associated with increased anxiety, depression, and pessimism about the future (Mishel, 1988). If uncertainty occurs in families of children with CF, it can possibly have a negative impact on the health of those children.

A second variable in Rolland's (1987) classification schema of chronic illness is outcome. The extent to which the illness will be a likely cause of death and the degree to which it will shorten life-span will have a profound impact on how individuals appraise stressors of the disease, and since the usual cause of death for children with CF is respiratory failure (Nelson and Vaughan, 1987), a common cold may be interpreted as a crisis in these families because of its respiratory component.

The most crucial factor in outcome is the initial expectation of whether a disease will be a likely cause of death. CF is known to be the cause of early death in its victims. The "it could happen" nature of CF creates the possibility of over-protection by the family as they appraise events/non-events in the context of imminent death. Obviously, familial response to the onset of a common cold in the CF child will be different than when a healthy sibling has the same ailment.

Hyman and Woog (1982) list magnitude, i.e. the extent to which stressors alter life circumstances, intensity (precipitousness of the required change), and duration of stressors as important variables influencing appraisal. Obviously, families of children with CF are faced with stressors of great magnitude which cause complex, life-long changes in family functioning. From a time perspective alone, chest physiotherapy on a twice or more daily, lifelong basis (Nelson and Vaughan, 1987) may necessitate such a tight time schedule that forgetting to set the alarm for a given morning may throw the family into a crisis. When one takes into account the life-long therapy required by children with CF, and the extent to which this therapy can alter family functioning, Hyman and Woog's (1982) emphasis on intensity, duration, and amount of family change required helps explain how families appraise the stressors of CF.

In assessing the appraisal process, it is important to note that different family members may attach diverse meanings to the same event/non-event. For example, a school-age child with CF who needs to be hospitalized for intensive therapy during an exacerbation, may appraise the situation as very positive, because school can be missed. There is also the strong probability that other children with CF, with whom close friendships have been developed, will be hospitalized at the same time, making hospitalization socially gratifying. Additionally, hospitalization frequently means extra family attention and gifts. Conversely, parents and siblings may appraise the same hospitalization as a crisis, because of the associated hardships and drain of resources, and the reminder of the ultimately fatal nature of CF. Parents will have to find time to visit the hospital during days that are already full of activity. If the distance to the hospital is far, travel expenses may be a burden. Siblings may become resentful of the extra parental attention attended the sick child, and the fact that they have to perform the chores ordinarily delegated to him. This example serves to point out again that events do not carry with them objective ratings of severity; this rating can only be the result of a subjective process of cognitive appraisal, which comes from the individual, rather than the event/non-event itself.

From this lengthy discussion of appraisal, it is apparent that appraisal is a complex process, taking into account a multitude of factors. The outcome of this process, however, can be described as the definition the family makes of the seriousness of the experienced event/non-event (McCubbin and Patterson, 1983). This subjective meaning is derived from the family's values, and its previous experience in dealing with stressors. Thus, a family's outlook can vary from seeing most stressors as challenges to be met, to interpreting most stressors as uncontrollable and an overwhelming threat to family functioning. Stressors that are appraised as challenges carry with them the possibility of growth and gain. Those that are appraised as threats may become crises that overwhelm the family's ability to cope.

Non-hassles In the proposed conceptual model, the appraisal process results in events being classified as non-hassles, hassles, or crises. Events which are classified as non-hassles are those day-to-day events which have been incorporated into a family's usual mode of functioning, and therefore, responding to them requires no unusual expenditure of energy.

A family's usual mode of functioning is not a situation which "just happens" as the result of parents and children coming together to form a family unit. Unlike an automobile, which functions in certain prescribed ways after being assembled, families develop a mode of functioning which is highly dependent upon feedback from previous experiences. When confronted with novel interactions with the environment (internal or external), organisms, from the moment of birth, respond in ways which in turn affect future interactions in an ever increasingly complex spiral of responses (Whaley and Wong, 1989). As families form, the various members bring with them feedback from all previous environmental encounters, which influences appraisal of, and responses to, subsequent encounters (Miller, 1980). Thus, situations which initially call for adjustment or adaptation of family functioning, eventually become incorporated into day-to-day functioning (McCubbin and Thompson, 1987). An example relevant to CF would be the chest physiotherapy performed on a daily basis, usually by parents, for children with CF. Initially, this task requires a major shift in family functioning to accommodate the extra time and energy involved. Eventually, however, chest physiotherapy becomes a part of the daily family routine, so it is appraised as a non-hassle. But if there arise associated hardships, such as unexpected additional time demands on a given day, performing chest physiotherapy may call for changes in family functioning and a revision of appraisal to hassle, or even crisis.

Hassles Hassles are the "irritating, frustrating, distressing demands that, to some degree, characterize everyday transactions with the environment" (Kanner, Coyne, Schaefer, and Lazarus, 1981, p. 3). Hassles are inclusive of relatively minor stressors of everyday life, such as getting caught in traffic jams, misplacing things, or breaking a shoelace. Because the unit of stress in hassles is relatively small, and the stressor so common-place, they are usually taken for granted and considered less important than more major life events (Kanner et al, 1981). But as common-place events, hassles can accumulate, and everyone has experienced days when nothing goes right. Such days can happen through the coincidental occurrance of several small events (e.g. a traffic jam, arriving five minutes late for work, receiving a parking ticket, and getting caught in the rain without an umbrella). And any single hassle may be the "straw that breaks the camel's back" (Zautra, Guarnaccia, and Dohrenwend, 1986), leading one to define an event/non-event as a crisis, rather than a hassle.

In the preceeding chapter, literature was cited which supported a positive relationship between reported hassles and somatic symptoms. How does this happen? In chapter I, the assumption was made that hassles require expenditure of energy and consequently, can be energy depleting. Children with CF are already in a precarious state, given their alterations in nutritional and respiratory status (Nelson and Vaughan, 1987). If energy is used to deal with hassles in the environment, less energy is available for meeting the demands of CF, e.g. increased work of breathing or impaired absorption of nutrients (Harris and Nadler, 1983).

Crises If an event/non-event is perceived to be a "sharp or decisive change for which old patterns of functioning are inadequate", it is defined as a crisis (Hill, 1958 A). Crisis is characterized by the "family's inability to restore stability, and by the continuous pressure to make changes in the family structure and patterns of interaction" (McCubbin and Patterson, 1983, p. 20). A crisis taxes or exceeds the family's ability to deal with its associated hardships, and involves major change in family structure and patterns of interaction in order to survive (McCubbin and Thompson, 1987). Conversely, if families are able to use existing resources to resist systemic change and maintain stability, stressor events do not become crises.

Obviously, because major changes in functioning are required, crises are energy depleting, with the potential for unfavorably influencing health. This relationship has been shown in Chapter II of this paper. But crises are generally acute/non-recurrent stressors, with defined start and stop points (Zautra, Guarnaccia, and Dohrenwend, 1986). Resolution of a crisis shunts energy back into the family system. Hassles, on the other hand, tend to be chronic/recurrent in nature, leading to continuous "dribbles" of energy as families deal with them. Additionally, crises may be dealt with more effectively and expediently than hassles, because they are taken more seriously (Kanner et al, 1981). Crises are hard to ignore, and demand some change in family functioning which, if successful, would allow for a return to a state of equilibrium. These characteristics of hassles and crises are advanced as plausible explanations to support data showing the relationship of hassles to decline in health.

Crises may arise, not only as the direct result of an interaction with the environment, but also indirectly from the effects of dealing with these interactions. In other words, families may experience crisis not as a result of the hardships inherent in the stressor situation, but also from the trial and error efforts to manage the situation (McCubbin and Patterson, 1983). Thus, crisis may not occur as the result of families having to provide chest physiotherapy daily, but from the acting-out behavior of siblings who resent the extra time parents spend performing the activity.

Responses, adjustment, and adaptation Following the assignment of events as either non-hassles, hassles, or crises, there occurs a response, during which an attempt is made to return to a state of equilibrium (McCubbin and Figley, 1983). To respond is to "make a reply or answer; to act in return" (Morris, 1982). For a response to occur, there must be an antecedent stimulus (McCubbin and Figley, 1983). In the proposed conceptual model, a response occurs after the event/non-event has been appraised and categorized.

Responses to events/non-events are influenced by the resources brought to the situation and the appraisal process. The latter concepts, resources and appraisal, have been discussed at length earlier in this paper, and their meaning remains constant when applied to the response stage in the conceptual model. The difference is that, whereas previous discussion centered around forming a definition of an event/non-event, the application now refers to the influence of resources and appraisal on the active stage of making a response. The following example serves to demonstrate a response to a perceived hassle.

If the mother of a child usually provides chest physiotherapy, but becomes ill herself, the task will need to be performed by another family member. Assuming that this represents a small change in function, the situation would be appraised as a hassle, based on the assessment that there are resources available (time and energy) to meet the demands of the situation. Then, at the response stage, these resources are actually used, e.g. getting up one-half hour earlier, or adjusting one's usual morning appointment schedule, to manage the hassle, and return to a state of equilibrium.

The outcome of response to hassles is shown in the conceptual model to fall on a continuum of adjustment, ranging anywhere from bon-adjustment to mal-adjustment. To adjust means "to change so as to match or fit" (Morris, 1982, p. 16). Obviously, if adjustment occurs in response to hassles, which are relatively minor stressors, the adjustments made are correspondingly minor (Kanner et al., 1981). In the description of hassles earlier in this chapter, it was noted that responses do not tax or exceed the family's ability to manage them. It appears, then, that resources are adequate to deal with the hassles, but that they may need to be manipulated, as in the previous example of getting up thirty minutes earlier to perform chest physiotherapy.

In the preceeding example, adjustments were made that returned the family to a state of equilibrium, and bon-adjustment was the outcome. Conversely, efforts at adjustment may be unsuccessful, leading to mal-adjustment, and a continuing or worsening of the disequilibrium (McCubbin and Thompson, 1987). Getting up thirty minutes early could just as easily lead to mal-adjustment, if corresponding changes in the substitute caregiver's personal schedule were not planned for, resulting in missing a school bus or forgetting to take homework to school. In mal-adjustment, the hassle is not managed, and new stressors are added to the situation, because someone will have to transport the child to school, and the forgotten homework may mean a lower grade.

If events are appraised as crises, efforts made to return to a state of equilibrium result in adaptation, falling somewhere on a continuum from bon-adaptation to mal-adaptation. Although McCubbin and Thompson (1987) include adaptation as a major concept in their T-Double ABCX model of family adjustment and adaptation, their efforts to define the word leave the reader somewhat confused. What does emerge clearly in their discussion is that adaptation involves major changes, that it occurs over time, and that it involves both individual-to-family, and family-to-community changes in functioning. Resources are taxed or inadequate, and former structure and patterns of family functioning are inadequate (McCubbin and Thompson, 1987). Help will probably need to come from outside the family system,and family roles may undergo significant changes.

The hospitalization of a child with CF is often appraised as a crisis, because it is a situation which calls for major changes in family functioning. Hardships associated with hospitalization might be extra time for hospital visitation, breakdown of the already old and undependable family car, and the extra expense of buying fast-food for the family if the mother is not there to cook meals. Responses might include going without sleep for prolonged times, having siblings do the housework (change in role), getting a loan for a new car, or asking a relative for temporary live-in help.

If changes are successful at resolving the crisis of hospitalization over time, bon-adaptation will result (McCubbin and Thompson, 1987). But if, for example, having a relative live in to help causes increased discord among family members, mal-adaptation results, and family disequilibrium continues or worsens.

The feedback loop The final step in the proposed conceptual model is the feedback loop. It is shown to occur following attempts at adjustment or adaptation. This is somewhat misleading, unless one follows the loop and determines that feedback is shunted back into both the early appraisal and later response stages of the model, influencing the outcome of these stages. From a systems perspective (Hazzard, 1971), feedback is the return of a portion of the output of any process or system to the input. More generally, feedback is any information about the result of a process. This information is used both in appraising whether events/non-events are non-hassles, hassles, or crises, and in determining how to respond to them. Logically, if a problem has been dealt with successfully in the past, feedback (information) about this previous success will influence how similar problems are appraised in the future. In like manner, unsuccessful encounters provide information that will exert negative influence on future appraisals (Lazarus and Folkman, 1984).

If one has been successful in dealing with a certain stressor, skills are developed which become resources for dealing with future stressors. Also, a sense of accomplishment increases self-esteem and a feeling of self-efficacy which is fed back to affect future encounters with events/non-events. Conversely, following unsatisfactory attempts to deal with present stressors, individuals may feel helpless to deal with future stressors. Or, from a positive perspective, feedback from unsuccessful attempts may motivate individuals to seek new and better responses. Thus, feedback can influence how one appraises stressors, and how these stressors are dealt with.

Because family hassles are continuous in nature (Kanner et al., 1981) there is the distinct probability that families are undergoing multiple hassles at any given time. These hassles may result in a pile-up of associated demands, which cumulatively result in an exhaustion of resources available to deal with them. At this time, the pile-up of demands may lead to a crisis. A crisis appraisal is the result of feedback of information indicating an exhaustion of resources for dealing with multiple stressors.

Stressors, whether hassles or crises, are accompanied by certain inherent demands. But positive efforts to deal with these stressors may create additional demands of their own. In a previous example, it was suggested that a family might obtain a loan to purchase a reliable car to solve the problem of transportation when a child with CF was hospitalized. The monthly payments associated with the loan, however, may be very difficult for the family to handle, and what began as a positive effort to manage is fed back into the system contributing to pile-up.

Families of children with CF are undergoing chronic, on-going stressors as a result of caring for the ill child. If the demands of caring for this child exhaust family resources of time, energy, and money, the information is fed back into the system via the feed-back loop, and the next stressor that occurs may be appraised as a crisis, even though it is relatively minor. The first stressor has not successfully been dealt with before another one emerges. As a result, there occurs a pile-up of demands, which, through feed-back, will influence appraisal of, and responses to, ensuing events/non-events.

Feedback, as a concept, can be either positive or negative in its influence on appraisal and responses. Positive feedback is exemplified in a sense of efficacy, growth of competence, and the joy of triumph against adversity (Lazarus and Folkman, 1984). Negative feedback contributes to a sense that certain responses will be ineffective for a given event/non-event. Negative feedback may also lead to a sense of incompetence and inadequacy.

Positive and negative feedback are not necessarily correlated with desirable and undesirable outcomes respectively. Positive feedback about the effectiveness of certain responses may lead to the incorporation of a standard response, quelling any impetus to seek new and better response patterns. And negative feedback may stimulate the search for improved ways of responding to events/non-events (Lazarus and Folkman, 1984).

Consider the family of a school-age child with CF that does everything as a family unit, from grocery shopping to nights out to vacations. In such a family, positive feedback may inhibit the trying of different response modalities, such as some individual time for family members, or for parents to go out alone on occasion. These new responses would probably lead to growth and development of family members (Phipps, 1980), but they may not be tried unless the family receives some negative feedback about former ways of functioning.

Summary of Discussion of the Proposed Conceptual Model

In Chapter III, a conceptual model has been advanced to show the relationship of family hassles to the health of children with CF. The model shows an event/non-event initially being appraised as a non-hassle, a hassle, or a crisis. Following this designation, responses are made. Non-hassle responses do not take extra energy, because they are a usual and expected part of life. Hassles and crises, however, require extra expenditures of energy, which may or may not be available. Regardless, energy spent dealing with hassles and crises is energy that is not available to children with CF, as they deal with the disease and its associated hardships.

The conceptual framework developed in this paper is viewed as a family model because it is used to describe behaviors of each individual family member which impact upon family functioning. Since the model is grounded, in part, on systems theory (Hazzard, 1971), it is essential to establish how individual behaviors impact family functioning, and vice versa. The author concedes that, at this point in time, it is not known if a cumulative score of hassles experienced by individuals really yields a family hassles score. Future studies, based on this model, may give guidance to the development of family hassles scales.

Although hassles are the concept of major concern in this model, the presence of life stressors is continuous and circular, and it is impossible to understand hassles without also understanding non-hassles and crises. And special circumstances surrounding what would normally be appraised as a non-hassle may turn it into a hassle. If hassles overwhelm the capacity to adjust, a crisis often ensues. For that reason, all three concepts appear in the model, and all three have been discussed in detail.

The conceptual model assumes a family systems approach (Hazzard, 1971), whereby circular causality dictates that what happens to each family member impacts on all members. This is the basis for predicting that hassles experienced by family members cumulatively will have a negative impact on the health of the school-age child with CF.

In the following chapter of this paper, implications of the concept of family hassles and health to the clinical nurse specialist in primary care will be discussed. Imogene King's theory for nursing will be used to explain the role of the clinical nurse specialist in facilitating the adaptation of families of CF children to the everyday hassles they encounter.

CHAPTER IV

IMPLICATIONS FOR PRACTICE, EDUCATION, AND RESEARCH

In the final chapter of this scholarly project, the nursing theory of Imogene King (1981) will be presented as a means to guide the practice of Clinical Nurse Specialists (CNSs) in primary care who work with families of children with cystic fibrosis. Integration of King's theory with the conceptual model proposed in Chapter II will be discussed. The role of the CNS in primary care will be discussed, and implications for nursing practice, education, and research will be presented.

Imogene King: A Theory for Nursing

In developing her theory for nursing, King addresses a dynamic state, whereby humans exchange energy and information between the person and the environment. Thus, King subscribes to an open systems philosophy in which personal, interpersonal, and social systems interact with each other. Her theory is labeled a theory for goal attainment, and it is based primarily on the interpersonal system, i.e. the interaction between the client and the nurse (see Figure 3).

Although King's theory is primarily concerned with the interpersonal system, she also stresses that an understanding of the way human beings interact with the environment to maintain health is essential to nurses (p. 2). Reference is made to both the internal and external environment. King does not imply that the environment is an immovable force to which humans must conform, but that a major responsibility of nurses is to assess the environment, and facilitate change in the environment, or in the individual, to promote health.

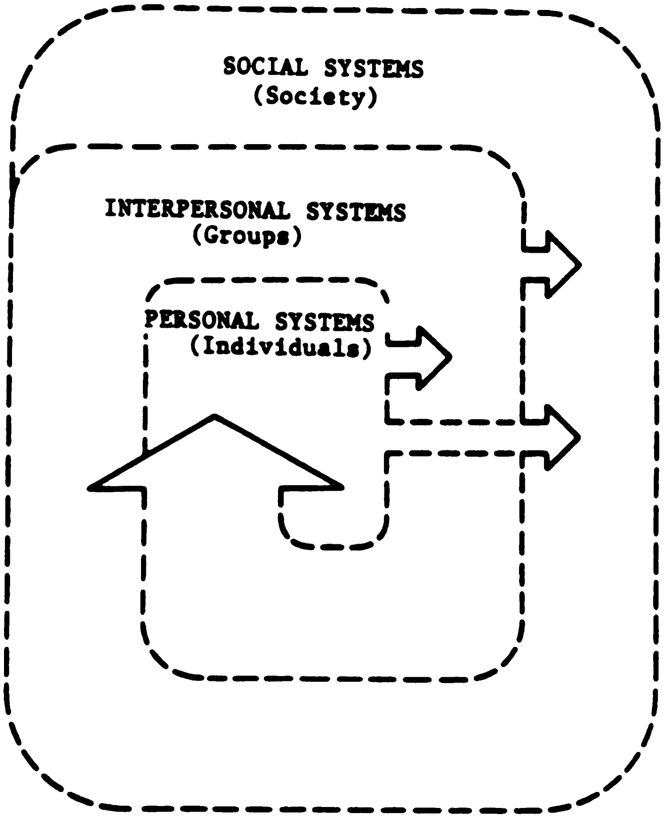


Figure 3: A conceptual framework for nursing: dynamic interacting systems. Adapted from King (1981),p. 11.

In King's theory for goal attainment (see Figure 4), health is given a high priority in the values of contemporary society. King's definition of health is:

> Dynamic life experiences of a human being, which implies continuous adjustment to stressors in the internal and

external environment through the optimum use of one's resources to achieve maximum potential for daily living (p.5). King's definition of health is consistent with the conceptual model developed earlier in this paper (see Figure 2, Chapter III).

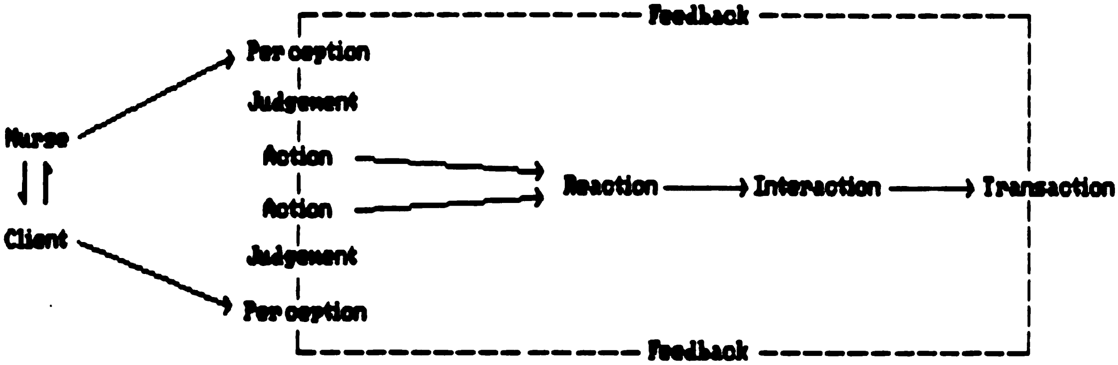


Figure 4: A process of human interaction. Adapted from King (1981), p. 11.

Families of children with CF are shown to undergo ongoing stressors, directly from the disease itself, and indirectly from the treatment for the disease. Stressors might be internal, as in the case of deterioration of pulmonary function or decline in weight for children with CF. They may also be external, as illustrated by financial strain related to hospitalization of the sick child. Another external stressor frequently experienced by CF families is the lack of time for family activities, secondary to the time commitment necessary to provide chest physiotherapy for the child with CF.

According to King, individuals are continuously responding to stressors, and trying to adjust through successful use of their resources. Because responses require energy, there is the possibility that depletion of energy may occur, especially if there occurs a pile-up of stressors which tax or exceed available resources. It is at this point, when existing resources become inadequate, that stressors interfere with health and the maximum potential for daily living. If resources are inadequate, the CNS must assist clients in obtaining the resources necessary for adjustment or adaptation to the stressors which are present.

King asserts that the goal of nursing is to help individuals maintain their health so they can function in their roles (pp. 3 and 4). The domain of nursing includes promotion of health, maintenance and restoration of health, care of the sick and injured, and care of the dying (p. 4). King's definition of nursing is as follows:

> A process of human interactions between nurse and client whereby each perceives the other and the situation, and through communication, they set goals, explore means, and agree on means to achieve goals (p. 144).

The human interaction between client and nurse, which is the basis for King's nursing theory, is initially influenced by perceptions of the situation, as well as perceptions of each other.

Perception is a process of organizing, interpreting, and transforming information from sense data and memory. Thus, perception is seen to emanate not only from the situation at hand, but also from previous life experiences. Perception gives meaning to one's experience, influences one's behavior, and, above all, represents one's image of reality (King, 1981, p. 24). In the perception phase, the stressor event is appraised for severity and meaning through the process of cognitive appraisal (Lazarus and Folkman, 1984). Additionally, clients evaluate how effective they think they will be in dealing with the stressor. The client also develops a perception of the nurse. A caring attitude, the sincere desire to help clients, and knowledge all enter into this perceptual image held by the client.

An important aspect of this nurse-client interaction is the verification of each other's perceptions as they plan together to achieve goals (King, 1981, p. 26). Perceptions, rather than events themselves, represent reality. It is essential for nurses to have a knowledge of client perception if they are to help in the identification and achievement of goals. Verification of perceptions can occur through verbal or non-verbal communication. The nurse's perceptions of the situation and the client must be based on an accurate assessment of developmental level, knowledge, resources, previous experiences, and emotional state.

In applying King's theory for nursing to the care of families of CF children, the nurse must remember that perceptions held by various family members as to the severity of any given stressor may be markedly diverse. Therefore, before making any progress toward goal attainment, the unique perception of each individual family member for a given stressor must be assessed. Obviously, the "opportunity" for the CF child to stay home from school with sickness will be perceived as very stressful by a parent who needs to work outside the home for financial reasons, but who will have to miss time on the job to care for the sick child.

The outcome of perception is judgment, whereby the client determines if the nurse can offer help. Similarly, the nurse makes a judgment as to whether or not she can help the client. For example, the CF child may need help in dealing with being "different" from other children in activity tolerance, and might perceive that the nurse can help his or her adjustment to the stressor. The nurse, in turn, perceives the need for help, and determines that she can offer the needed assistance. At this stage, the process of interaction begins.

Elements of the interactive process include action, reaction, and transactions. King provides vague and sometimes overlapping descriptions of these concepts, but it appears that after the judgment is made to offer (nurse) or receive (client) help, the two individuals mutually identify goals and explore the means to achieve them. This response is the action, and it initiates interaction of nurse and client working toward attainment of goals. For example, the nurse and the client might mutually agree that a weight gain of five pounds within the next month is an appropriate client goal, and they explore strategies to meet this goal in the action phase.

The reaction occurs in response to action. Reaction represents the actual steps that are taken to achieve the goal. In the above example, reactions might be having a high-calorie snack at mid-afternoon and bedtime, and eating extra portions of bread with meals. If the goal of a five pound weight gain in met, transaction has occurred. Transaction is seen as the outcome of a successful nurse nurse/client encounter.

Throughout this interactive process, presenting conditions are recognized and goal-related decisions are made. Actions are taken to achieve the goals. Transactions, or attainment of goals, result in satisfaction, effective care, and enhanced growth and development.

King's model depicting her theory of goal attainment in nursing shows a feedback loop from transaction (goal attainment) back to perception. Curiously, the model implies that all interactions between client and nurse result in the attainment of goals. These positive outcomes then influence future encounters with the environment. For example, successfully dealing with the stressors of a CF child's hospitalization may increase self-confidence and help instill an "I can do it" attitude when similar stressors present in the future.

But anyone who has even remotely observed human experiences realizes intuitively that such an ideal situation does not always occur in day-to-day living. Indeed, a more accurate representative portrayal would show a lack of goal attainment as an alternate outcome, with feedback from this unsatisfactory situation traversing the feedback loop to influence future perception of events. Negative feedback might lead to a lack of self-confidence and a feeling of low self-efficacy.

As a chronic, potentially fatal childhood illness, CF can appropriately be considered within King's stated domain of nursing, i.e. care of the sick, and ultimately, care of the dying. The ongoing, continuous, disruptive nature of the disease and its treatment adapts easily to King's definition of health as a continuous adjustment to stressors in the internal and external environments.

King's theory of goal attainment can logically be applied to nursing care of families with CF children. Because CF is chronic, and characterized by remissions and exacerbations, most of these children have frequent access to the health care system. Even if the disease is stable, and an affected child's health is relatively good, routine follow-up visits with the care provider are scheduled every six months. Consequently, these families can usually be worked with in a longitudinal fashion. Establishment of an ongoing relationship between family and nurse would naturally enhance any goal attainment which is based on an interaction model, such as that advanced by King.

Utilizing King's theory, the client is not just the child with CF, but also each family member. Because families are open systems, the experiences of each member affects all other members in circular fashion (Hazzard, 1971). That is the basis for the question posed in this paper, ie. What is the relationship between the health of school-age children with CF and the hassles experienced by their families?

Current research fairly conclusively supports a positive relationship between stressors and health. Because of this, nurses help clients identify stressors and manipulate resources in such a way as to adjust to the stressors (goal attainment). If resources are inadequate, assistance is given to the client to obtain the necessary resources. Resources commonly identified as important to families with CF children are time, money, knowledge, and social support. If the nurse assumes that stressors can negatively impact on the health of CF children, resource allocation becomes an important focus of her care.

Cystic Fibrosis in Primary Care

Primary care is principally community and ambulatory based, and is characterized by accessibility, comprehensiveness, coordination, continuity, and accountability. Its content is health maintenance, reasoned screening, management of common and simple illness, monitoring of chronic illness, and achievement of a dignified death (Mauksch, 1981). Primary care is provided by physicians, CNSs, nurse practitioners, and physician assistants.

Many children with CF are cared for in a major CF center. Others, who may live a great distance from one of these centers, will receive care from non-specialized providers. Even when children receive CF care at a major center, parents are encouraged to also have a primary care provider who manages other aspects of the child's health or illness. It cannot be forgotten that these children will need the same immunizations, developmental screening, anticipatory guidance, and care for usual childhood illness as will their healthy counterparts.

Of course, this primary care needs to be coordinated with CF care, but emphasis must be placed on the child as a developing being first, rather than "a case of CF". Hopefully, this type of focus by health care providers will provide helpful role modeling for parents of these children. It is easy for parents to respond to their chronically ill children by being over-protective, and not allowing them to participate in activities which are critical to the development of healthy ego identities. But if primary care providers are emphasizing the "normal" aspects of these children, parents may find it easier to realistically assess their child's developmental needs and capabilities.

If communication with the CF specialists is carefully maintained, the CNS is an ideal person to provide primary care for children with CF. Perhaps the best situation would be for the CNS to have a joint practice with a physician provider. This would allow her to concentrate on what nursing's focus is, ie. assisting clients to adapt to real and potential states of disequilibrium, while providing a ready source of referral for problems outside her scope of practice.

Implications for Advanced Nursing Practice

Cystic fibrosis is a complex disorder which imposes multiple stressors on both affected children and their families. These families require ongoing care because the disease is never cured. The ultimate early death experienced by these children adds yet another dimension to the manifold problems undergone by families with chronic illness.

Nurses in advanced practice who work with CF families are first and foremost concerned with the health of these children. But the focus of the CNS goes beyond the pathophysiology and medical treatment of the disease. Because nursing is defined as the diagnosis and treatment of human responses to actual or potential health problems (American Nurses Association, 1980, p. 9), the CNS must continually assess her CF clients' and families' responses to the stressors of the disease and its treatment.

In Chapter III, a conceptual model was presented to show how stressors are defined and managed by CF children and their families. Since dealing with multiple stressors requires energy, a pile-up of stressors could conceivably affect the health of these children, because less energy would be available for physiological responses in day-to-day living. This viewpoint has been supported in the literature (DeLongis et al., 1982; Kobasa, 1982; Locke, 1982; McCubbin et al., 1983; Sarason, 1985). It seems prudent, then, to assume that a major focus of the CNS should be to help the family identify stressors, decrease the numbers of stressors, when possible, and assist them to deal more effectively with those stressors which are inevitable.

Identification of Stressors Many stressors associated with CF are obvious to families because they require major changes in function. There are many other stressors (hassles), however, which are more subtle, and which may not be recognized as having any impact on the health outcome of CF children. Hassles are "minor" occurrences which happen daily in the lives of everyone. But in CF families, additional hassles arise which may be associated with family attempts to manage the disease and its treatment.

A way to help families identify hassles would be to have school-age and older family members complete a modified, shortened hassles checklist. Pre-school children could be interviewed to get insight into what events they perceive to be hassles. As an initial step, hassles checklists serve to increase awareness of the common hassles families experience. Additionally, when there is a decline in the CF child's health, as evidenced by a decreased Swachman score or the need for hospitalization, a time-line of hassles, looking retrospectively, might demonstrate to families the relationship between hassles and health. This perspective might motivate family members to try to eliminate hassles, when possible, or deal with them more effectively.

When helping family members identify hassles in their lives, it is important for all members to understand the hassles being experienced by each other. A family meeting with the CNS could be planned during which hassles of all family members could be shared. The CNS will need to guide this type of session carefully so it remains a vehicle for promoting understanding of, rather than placing blame on, each other. In planning this family session, the CNS remembers that one of the characteristics of primary care is accessibility. For this reason, it may be necessary to schedule an evening home visit, to accommodate family work and school schedules.

Since school-age children with CF are being considered specifically in this paper, it would be helpful for the CNS to discuss the health impact of hassles with school personnel. Roughly seven hours per day are spent in school; consequently, many hassles are likely to experienced in the school setting. Teachers could be helpful in two ways. They could first identify for the CNS the types of school-related hassles children are likely to encounter. Secondly, teachers could assist CF children to deal more successfully with hassles. Teaching time-management skills might help eliminate some hassles. Relaxation training could alter physiological responses to hassles. These two techniques traditionally are part of stress management programs for adults, but many researchers are recognizing that children, too, can profit from learning them.

When taught time-management and relaxation techniques, students with CF would not need to be singled out as different from their peers. These skills could be taught to all children as part of health education. There would be peer support for engaging in the behaviors. From a developmental perspective, peer support and acceptance become increasingly important during the school years (Erikson, 1963; Whaley and Wong, 1989).

The CNS must continue to help CF families assess for the presence of hassles on a continuing basis. As family members grow and develop, perspectives will change. Anticipatory guidance, i.e. discussing with individuals what they can expect to encounter at different times in their lives, will help them be more aware of ongoing hassles, and better prepared to deal with them.

In the process of assisting CF families to identify hassles, the CNS functions primarily as an assessor. But she also works to teach family members to become assessors, as well. By teaching this assessment skill to family members, the CNS empowers them, promoting a sense of independence and self-efficacy. Therefore, a second characteristic displayed is that of educator.

The identification of hassles occurs an the perception phase of King's (1981) process of human interaction. The nurse and the client have come together, and each is perceiving the situation to determine if hassles exist. Because perception is one's concept of reality, the nurse must know what her clients define as hassles, before she can help them respond in a satisfactory manner.

Clients may need help in defining hassles. In contemporary society, major life stressors are given more attention for their affect on health than are micro-stressors, or hassles. For this reason, individuals may not see the importance of identifying hassles. By directly querying individuals about hassles, the CNS validates their importance as a factor in health status.

At this early stage of the interactive process, it is imperative that the CNS define her helping role with the CF family. If the definition is vague and ambiguous, families may expect either more or less help, or different kinds of help than assumed by the CNS role. Good early questions to ask would be "What are your goals?" and "How would you like me to help you meet your goals?" Of course, the CNS role may change as family needs change, so it would be wise for the CNS to redefine her role with the family on an annual basis, to be certain family and CNS perceptions are congruous.

Decreasing Hassles/Modifying Responses to Hassles Frequently, measures taken to reduce the number of hassles, and to alter how one responds to them are interrelated. Single nursing interventions may actually lead to the achievement of both outcomes. It is for that reason that both concepts will be discussed in this section of Chapter IV.

King (1981) suggests strategies for goal attainment in her theory for nursing. She refers to goal attainment as transactions, and asserts that successful transactions depend upon mutual goal setting. In other words, the nurse and the client must share a common goal. In the context of this paper, the common goal would be alleviation of hassles, or modification of responses to the hassles.

To accomplish mutual goal setting, the CNS functions in the role of planner. A planner is "one who develops goal directed strategies in collaboration with the client to facilitate maintenance and achievement of health-oriented goals" (Michigan State University, 1986, p. 18).

The CNS initially determines goals of hassles management which each family member has developed. She must then assess whether or not these goals are realistic or appropriate. For example, if the child with CF sets a goal of "beating up" his tormenter when teased about small stature, frustration and anger will result not only toward the offending child, but also with him/herself because the goal is unattainable. The child can be counselled to set a more realistic goal, such as remembering to respond to being teased by stating a positive self-attribute. This tactic disarms his foe, and forces the child to identify positive self strengths, such a patience, intelligence, or kindness.

When hassles are not effectively dealt with, they may pile-up and lead to crises (McCubbin et al., 1983). In an attempt to help families eliminate, or deal effectively with hassles, the CNS can teach time management skills to all family members. There is no doubt that the treatment of CF requires an extra time commitment, and inefficient use of time by family members can easily lead to crises. Keeping lists and schedules of "things to do" can be suggested as a means of managing time. Time management in the school setting has already been discussed. Besides helping to decrease unnecessary hassles, time management might also contribute to a sense of control and accomplishment.

It was pointed out earlier in this chapter that about seven hours of a school-age child's day are spent in school with peers. Many of the hassles that confront these children in a school setting arise because peers and teachers do not understand CF. As a result, they concentrate on how CF children are different from, rather than similar to, themselves. The CNS can visit the classroom, emphasizing that the disease is not contagious, and explaining its visible aspects such as small stature, persistent cough, exercise intolerance, and enzyme replacement with meals. This understanding will replace fear and ignorance, increase peer acceptance, and provide valuable social support for the CF child.

Several researchers have shown that most CF families adjust satisfactorily to the disease and its hardships, and that it is important to assess family strengths, rather than just family weaknesses (Cowen et al., 1985; Gibson, 1988; Stullenbarger et al., 1987). By pointing out strengths to family members, nurses reinforce their feelings of self-efficacy and control. In discussion of the proposed conceptual model in Chapter III, self-efficacy was shown to be an important consideration in how one perceives stressors, and the ability to manage them (Clark et al, 1987). Self-efficacy is strengthened by the positive reinforcement provided by the CNS.

Resources are known to be an important factor when assessing how family members deal with hassles (McCubbin, 1983). When resources are strained or inadequate, CF families may experience increased hassles, which could conceivably lead to crises. A resource which is commonly strained in CF families is money. Expensive medication and equipment, special food, frequent health check-ups, and hospitalizations all contribute to CF related expenses. In Michigan, children with CF receive assistance from Crippled Childrens Services (CCS), which is administered by the local department of public health. But it is well documented that with CF, there may be five to ten thousand dollars per year extra expenses which are not covered by any type of insurance (Lewiston, 1985). These extra expenses include travel expenses to the CF center, purchasing prepared meals for the family at home during a CF hospitalization, or missing work to care for the CF child when he is too sick to go to school.

The CNS must determine what resources are available in the community which would supplement CCS or private insurance. Sources might be churches, professional service organizations, and special interest groups. Accessing sources of assistance can be a confusing process for families, and the CNS can use her knowledge and expertise to facilitate the process.

Another resource which is important for the CNS to consider when working with CF families is social support. Yarcheski and Mahon (1986) showed that social support may decrease the family's vulnerability to stressors. With chronic illness, support systems act to share the burden of the illness. The most important social support is the family, and a crucial variable in family sharing of the burden is the ability to communicate (Holaday, 1984). The CNS should assess the quality of family communication, and institute ways to improve communication, when indicated. A practical way to increase family awareness of their communication would be role-playing in a family setting. Family members can be assigned each others roles, and given situations to act out. Role-playing can also be used as the family tries out the communication techniques taught by the CNS.

Social support for parents may be received from parent-to-parent support groups. These groups help reduce stressors because they increase the parents' understanding of their CF child's illness and care management. Support group participation also acts to clarify misconceptions, share coping strategies, and increase awareness of individual/family way of dealing with strategies. Honesty, understanding, and support seem to be key ingredients in the success of these groups. The CNS refers parents to an existing support group, or assists them in establishing one, if necessary. Consideration should also be given to the establishment of a support group for siblings of the CF children to help them deal with their own unique stressors.

The CNS needs to recognize herself as an important source of social support for CF families. Her relationship is on-going, and the emphasis on holism assures a supportive relationship with these families. It is important for the CNS to continue this helping relationship when these children are hospitalized, since the hospitalization experience is a time when family stressors are certain to be increased. In attempting to decrease the incidence of hassles as much as possible, the CNS collaborates with the health care team to assure that client and professional goals are the same, so that goal attainment is a realistic, expected outcome. The CNS should participate in formulating the written hospital plan of care, and should make herself available as an expert for consultation in matters related to CF children and their families. Hospital privileges should be a negotiated part of the CNS' work contract, so that there is the flexibility of being available to CF families during other than the traditional eight-to-five work hours.

In addition to inadequate resources, altered childrearing practices may contribute to stress in CF families. Because CF is genetically determined, parents may feel a burden of guilt. This guilt often interferes with the development of realistic expectations for the CF child, and difficulties with discipline may arise. Holaday (1984) discusses the concept of normalizing as being helpful to CF family functioning. In normalizing, the CNS directs parental efforts toward shaping and maintaining their child's physical and social normative skills. School attendance, appropriate peer activities, realistic discipline, and future planning should be encouraged by the CNS. Cystic Fibrosis Camp is an outstanding example of normalizing, because it allows these children a chance for a summer camp activity, while receiving the intensive CF treatment which is a part of their everyday lives.

Parents can be encouraged to work with social systems, such as school or government, to help change policy which would contribute to the integration of the CF child into the mainstream. This activity would promote normalization. If this type of involvement is a novel activity for CF families, they will profit from CNS guidance. Providing the names and addresses of legislators, and describing the legislative process are practical ways to assist parents to become change agents.

Normalization strategies may lead to several useful outcomes for families. First, normalization minimizes the impact of the chronic illness by maximizing the child's abilities. Parental anxiety will be reduced, and they will experience a sense of hope for a better future for the ill child. The child will become more independent and skilled in self-care, which will permit parents more time and energy to devote to other activities.

Venters (1981) discusses the need for families with chronic illness to endow the illness situation with a personally significant meaning as a way to decrease vulnerability to stressors. Assigning a meaning to events leads to establishment of feelings of mastery and self-sufficiency by family members. Feeling of mastery and self-sufficiency, in turn, decrease the number of hassles experienced because stressors would tend to be taken in stride as manageable and a normal part of adjusting to the illness. The search for meaning seems to provide motivation to meet and manage hassles, and to strive for achievement in the face of trouble.

A search for meaning can take different forms. Families with a strong religious background may define the illness with a religious philosophy. Strong support is provided when the family sees the illness as a planned part of their lives (Gibson, 1988). The CNS can assess what meaning is given the illness by asking family members "What does it mean to you to have (CF) (a child with CF) (a brother or sister with CF)? If a spiritual meaning is assigned to CF, the CNS should ascertain who the spiritual support person is (minister, priest, rabbi, etc.) and educate that support person fully about CF.

The family may also search for meaning from a medical and scientific approach. They study the etiology of the disease, as well as current means of treatment. Readings and discussions bring into focus what must be done for the child. The family learns which areas of the child's life and function are not affected by the illness, and can develop plans to ensure as much normalcy as possible. The CNS assists the family in this task by providing factual information about CF, and reinforcing attempts to learn more about the disease. If family members express an interest, they are encouraged to act as support persons for other CF families, to volunteer for the Cystic Fibrosis Foundation, and participate in fund-raising activities.

Individuals who have a sense of control and mastery over their own destiny can decrease hassles in their lives, or optimize their adjustment to unavoidable hassles (McCubbin et al., 1983). For this reason, the CNS encourages self-care activities in CF children at an early age. If these children assume responsibility for their own care rather than depending entirely upon parents, they are more apt to conform to care modalities during adolescence, a time when dependence upon parents is perceived to be unacceptable. In promoting early self-care, the CNS works not only with the child, but with parents as well, to develop realistic expectation.

As stated earlier, realistic expectations of CF childrens' abilities may be difficult for some parents, and feelings of guilt for passing the disease on may prompt parents to do more than necessary for the child. This situation is particularly apt to arise when parents do not have a future vision for their sick child. Helping parents develop a future vision assists them in understanding why self-care at an early age should be promoted. With modern treatment, over half of these children survive beyond twenty years (Taussig, 1984), so college and career planning are appropriate. It would be helpful for the CNS to have parents of well-adjusted CF adolescents meet with parents of younger CF children, to assist them in developing a future perspective.

Although the nursing practice implications which have been discussed in this section have primarily been directed toward the entire family, some special considerations need to be made for siblings of CF children. A crucial factor for the CNS to keep in mind is the developmental level of the siblings. This knowledge will aid in assessing the meaning siblings attach to the disease. Young children engage in magical thought, and may suffer immense guilt by thinking they caused exacerbation of the illness, or even death of their sibling, by thinking bad thoughts. Young children also may view the extra attention paid to their sick brother or sister as punishment to themselves by parents for some bad deed. Their understanding of illness causation may not be accurate, and fear of catching CF may be paramount in their minds (Whaley and Wong, 1989). As children grow older, and develop an accurate understanding of the etiology, they become aware of their chance of passing the disease on to future children of their own. Having a sibling die may evoke intense guilt at having been spared. It is imperative that the CNS discuss these developmental needs with parents, so parents can help the siblings deal most effectively with them.

Mayerowitz and Kaplan (1967) found that parents of CF children became very anxious when their healthy siblings asked about the disease. With this in mind, the CNS realizes that siblings may have many unanswered questions about the illness, and this knowledge deficit may contribute to anxiety and loss of control for these children. It should be part of family care for the CNS to meet with healthy siblings individually, to assess what their knowledge base about CF is, and provide factual knowledge which is cognitively and affectively appropriate for their developmental level.

Implications for Nursing Education

There are three major areas to which the CNS can direct efforts toward educating others about the relationship of the stressors of life to health outcomes. These areas are basic nursing education, continuing nursing education, and education of the public. The first area to be considered is the basic educational preparation of nurses in the various types of nursing curricula.

In many nursing programs, the concepts of adjustment and adaptation to life stressors, which form the basis of much of nursing theory, are an integral part of the educational philosophy. Nursing students are taught that no individuals lead stress-free lives, and that a major nursing focus should be directed toward relieving stress.

Many disease states are thought to result from chronic stress, and others are seen to be exacerbated by stressful conditions.

The curricula which currently graduate the majority of practicing nurses are those offering associate degrees in nursing. These curricula are typically about two years in length, and there is not much time to incorporate concepts of stress management into the avalanche of pathophysiology which is usually taught. Ways to reduce immediate stress in the illness situation are included (ie. pain management, a calm environment, attention to basic human needs), but empowerment of clients by teaching the stress reduction techniques they can incorporate into their own lives is not a major focus.

The CNS who sees the long-term benefits of teaching stress management can work at two levels. She can directly contact directors of nursing education institutions, and discuss her concerns about a more comprehensive inclusion of stress management teaching in the curriculum. She can also take her concerns to state boards of nursing, where policy is made. She should be thoroughly prepared to defend this stance, by being knowledgable about research findings in the area.

A second intervention relates to the need for inclusion of a course in nursing theory in nursing programs. Most nursing curricula are based upon a theoretical construct, which is commonly nursing theory. But in many educational programs, students are not exposed to the works of other nursing scholars. Thus, it is difficult for them to develop a framework to guide their own nursing practice. Faculty who have studied the advanced role of the nurse should teach students the advisability of developing a conceptual framework of their own, to guide them in an ever-increasingly complex practice setting. One of the best ways to incorporate a theory into practice is to have to defend it to others. This could be accomplished by having students present various nursing theories to their peers in the classroom.

Another major concern of nursing education should be to prepare beginning practitioners to read and critique research literature. This would be best accomplished through inclusion of a formal research class in the curriculum. Nurses are looked to as sources of accurate information by their clients and families, even while still in the student role. Also, with the current explosion of health care information, nurses must be able to intelligently choose the nursing interventions that research has shown to be the most efficacious in client care. Directors of Nursing (DONs) in health care institutions can further stimulate the interest in nursing research that was begun in the classroom by keeping recent copies of nursing research journals in conference areas and coffee-break rooms. DONs can also encourage interest in nursing research by scheduling inservice classes, in which nurses present various research findings, and discuss their application to their specific clinical areas. The CNS has a sound base in the research process, and she could act as both consultant and educator to other nurses.

Nurses who are concerned with helping families adapt to the stressors of chronic illness are finding that they need to be knowledgeable about home-care nursing. Even if they function primarily in an acute care institution (hospital), they need to prepare clients with chronic illness for supportive care outside the hospital after discharge. Children with CF often need nursing care in their home at the end-stage of their disease.

Within the last two or three years, the explosion in the need for home-care nurses has been phenomenal, and many hospitals operate their own home-care nursing agencies. If nurses are to provide quality care, which is focused on helping clients adjust and adapt to the stressors of their disease and its treatment, they must receive a firm base for home-care nursing in their basic nursing program. Home-care nursing must have a strong nursing theory framework, because many home-care interventions are not from a standard set of nursing interventions, but rather require judgment and creativity on the part of the nurse.

Another recommendation for nursing education is that change theory be included as a prominent concept in the curriculum. Management of life stressors is often dependent upon knowing how to make changes in organizations or institutions. Nurses need a good understanding of change theory, as well as how change can be accomplished in various institutions/agencies. With long-term, chronic illness, however, it is necessary that families themselves learn how to effect change that will benefit their functioning in the long run. Nurses have a professional obligation to educate families to become change agents.

The final recommendation for basic nursing education is the inclusion of study about community resources, and how to access them. In the conceptual model proposed in Chapter III of this paper, resources were shown to be a major factor, not only in how individuals perceived stressors, but also in how they responded to them. Community resources can provide material assistance, educational assistance, and social support, all three of which are critical to successful adjustment and adaptation. Many community resources are listed in telephone books under "Social Service Agencies". Students in a classroom could be assigned two or three agencies to research, and then all students could present their findings to classmates. This technique will provide students with information, and it also teaches them to be assertive when seeking resources for clients.

Continuing education for nurses is the second area of educational concern for the CNS in advanced practice. For nurses who have already completed their basic education, the CNS can offer to serve as a consultant for staff nurses, providing inservice on the long-term benefits of learning stress management. This information must be presented as a benefit both to nurses and to their clients. Actual techniques (time management, relaxation techniques, and values clarification, for example) should be taught, and opportunity for practice provided. Because these nurses should realistically teach these same skills to clients, the CNS must also provide the necessary information about teaching-learning theory, so teaching sessions will be effective.

Another aspect of continuing education for nurses to consider would be the possible presence of student nurses in client care settings. If the care setting is affiliated with a nursing educational institution, students could be encouraged to provide staff nurses with information about the relationship between stress and health. Planning and teaching inservice sessions could be incorporated as a clinical requirement in meeting the objectives of the course.

The CNS could approach professional nursing organizations, and work with them to provide seminars and workshops about stress and health for practicing nurses. Because of her advanced education, the CNS is well prepared to plan and coordinate these learning experiences, as well as to actually provide the teaching. Emphasis should be placed on stress management as beneficial both to nurses and to their clients.

The third area of educational focus for the CNS is at the community level. Obviously, the CNS can offer her services to various organizations that express an interest in the relationship between life stress and health. Many workplaces now include stress management programs as a benefit for their employees. The CNS could perhaps design a stress management program for employees, and contract to provide this benefit in the workplace.

Schools represent another important place for intervention by the CNS. Since this scholarly project is designed to study the effects of stressors on the health of children, the author proposes that the most effective educational intervention overall would be to go into the early grades, and teach young children stress management techniques. Perhaps teaching stress management as a lifestyle, rather than a panacea, would provide a better outcome than is currently being seen. Incorporation of stress management as an attitude at an early age would allow it to become an inherent part of living, rather than a new skill to be learned later in life.

Implications for Nursing Research

The conceptual model that was presented in Chapter III has not been tested as of this writing. It is based on systems and stress adaptation theories, both of which have been researched extensively. In reviewing research which was pertinent to the proposed model, the author found that, although research was plentiful, there were methodological problems which limited application of the findings. These weaknesses become the basis for many of the authors's recommendations for nursing research.

Several studies were found which purported to report how children responded to the stressors of chronic illness (Cowen et al., 1985; Stullenbarger et al., 1987; Venters, 1981). However, after studying these reports, it was found that, in the majority of cases, children were not directly queried about their own perceptions. Instead, parents, usually the mother, were asked how children responded to the stressors. Obviously, research has to get at children's perceptions in order to truly understand how they are affected by the stressors of chronic illness. This is not an easy task, given the varying cognitive levels of children of different ages. Perhaps the first step for researchers in this area is the development of data collection tools which would reliably elicit pertinent data from children themselves. Barnes, Peek, and Spence (1987) have developed a hassles measurement tool for children. Although their tool has had limited use, it shows promise of being able to accurately measure hassles in children.

Another methodological problem which was commonly noted in the research literature was the lack of longitudinal data collection. Data which is collected in a cross-sectional manner, does not provide information about the changes that evolve related to stress responses as children pass through various developmental stages. Longitudinal studies are time consuming and expensive, but they provide the best data for researchers interested in how children and their families manage stressor.

All studies found by the author which were designed to measure hassles collected data on hassles occurrence in a retrospective manner. Clients were asked to record the incidence of hassles that may have occurred as long ago as six months. Hassles are defined as minor annoyances, and as time goes by, the reporting of their perceptual significance is apt to be subject to recall bias. A more accurate reporting of hassles would occur through daily, diary recording techniques.

The tools which have been designed to measure hassles suffer from a lack of consensus over their reliability and validity. There is some concern that items which are labeled hassles are actually responses of individuals to stressors, rather than primary stressors themselves. Further research must be conducted to develop reliable and valid stress measurement tools.

Many of the research studies reported in this paper did not utilize control groups. Randomization of subjects was not done, so application of findings was limited. These are two methodological techniques which weaken the findings of the authors. Sound research design in imperative before research is begun.

Most of the research reported findings from intact, two-parent families. Given the trend toward single-parent families in contemporary society, it becomes necessary for research to target this growing population. Obviously, the stressors experienced in these non-traditional families can differ greatly from those in traditional families.

The Swachman scoring tool is currently used to measure health status of children with CF. But this rating system does not truly account for all the dimensions of health as defined in this paper. Nutritional status, respiratory status, and participation in usual activities are the only indices of health measured. Emotional status, self-efficacy, and self-concept are among some of the additional factors that need to be assessed. Further research needs to identity the best way to truly measure health from a holistic point of view, and these findings must be incorporated into the development of a valid and reliable tool to measure health.

From the research that has been completed to date regarding the relationship between hassles and health, there does appear to be a positive relationship. But it is unclear if this is a function of numbers of hassles, seriousness of hassles, or a combination of both factors. Future research that addresses this issue can provide further direction to the CNS who works with CF families.

Many researchers have shown that social support is very important in reducing vulnerability to stressors. Sources of social support have been identified, but this social support seems to be appropriate primarily for adults. None has really tried to ascertain what constitutes social support for children of different developmental levels. It is often reported that peer acceptance and support is critical for children, especially during adolescence. But are there other sources of support that are important to children? Do children with CF utilize social support which is different than their healthy counterparts? What kind of social support is important to siblings of

CF children? These are questions that must be researched, if the CNS is to provide clients and families with optimal social support to buffer stressors.

It has been noted that when children with CF participate in self-care and management of their disease at a young age, they are more likely to conform to treatment modalities when they reach adolescence. Children who instead have depended on their parents for CF care, are apt to become rebellious at parental attempts to manage the disease during the teen years, a time when separation from parental influence is a major concern. In the past, it was thought that the best way to encourage self-management was to provide information about the disease and its treatment. More recent research has shown that information alone is not sufficient to motivate individuals to self-care. If knowledge alone is not the answer, what is the best way to encourage early self-care activities in children when they are very young? Further research findings are necessary to guide the CNS in this area.

In summary, the author has pointed out the need for better design in future studies which measure stressors and their effects on individual and family functioning. The tools which are currently in use to collect pertinent data need to be refined. Attention must be paid to an emerging family system, ie. the single-parent family. Sources of childhood social support must be more clearly identified, and strategies to motivate children toward self-care activities must be defined.

Questions for Future Research

1. Is quantity or quality of hassles the more important predictor of health status for children with CF?
2. Is there a difference in the hassles reported by single- and two-parent families?
3. What strategies are most effective in promoting self-care of CF children at an early age?
4. What kinds of social support are most helpful for CF children of various ages?
5. What characteristics most accurately reflect the health status of CF children?
6. Do families report more hassles when children are in remission or exacerbation?
7. What strengths are identified in CF families that show effective functioning?

Conclusions

In conclusion, the relationship between the health of children with CF and the hassles reported by their families is an important question to the CNS in primary care. Although these children have a shortened life span, many are living into their twenties and thirties. Thus, they are experiencing not only the rigors of the treatment of the disease, but they must also experience the disease as they progress through many developmental stages. Obviously, types of stressors will change and vary with the developmental level of the children. The certainty of an early death adds a unique feature, not seen in all chronic illnesses. To tap the ever-changing stressors that accompany normative developmental changes, as well as those which occur secondary to deterioration caused by CF, studies based on the conceptual framework should be longitudinal in nature.

To date, no researcher has reported data collection from all family members to determine if family hassles impact on the health of CF children. In this scholarly project, the author has proposed a framework that could provide structure for research on the topic. Development of appropriate data collection tools remains to be improved, both to measure hassles occurrence and health as defined in this paper.

Recent research has shown that most CF families adjust fairly well to the disease, and continue to function satisfactorily. If this is the case, the conceptual framework could be utilized to determine family strengths, rather than just family weaknesses. Once strengths are identified, they become resources as families adjust and adapt to the stressors encountered in everyday life.

In summary, the concepts of hassles, chronic illness, and health have been explored and placed in a theoretical framework. Significance of the subject to the field of nursing has been established. Pertinent literature has been reviewed and critiqued. The concepts have been addressed in terms of roles appropriate to advanced nursing practice, education, and research.

Testing of the framework is the next step in the research process. Validation of its construct will allow other researchers to test the framework under different conditions, and using different variables. It is the author's sincere hope that use of the framework will ultimately improve nursing care of CF children and their families.

APPENDIX A

Swachman-Kulczycki System of Clinical Evaluation of Patients with Cystic Fibrosis

Swachman-Kulczycki System of Clinical Evaluation of Patients with Cystic Fibrosis

Grading	Points	General Activity	Physical Examination	Nutrition	X-Ray Findings
Excellent (86-100)	25	Full normal activity; plays ball, goes to school regularly, etc.	Normal; no cough; pulse and respirations normal; clear lungs; good posture	Maintains weight and height at above 25th percentile; well-formed stools, almost normal; good muscle mass and tone	Clear lung fields
Good (71-85)	20	Lacks endurance and tires at end of day; good school attendance	Resting pulse and respirations normal; rare coughing or clearing of throat; no clubbing; clear lungs; minimal emphysema	Weight and height at approximately 15th to 20th percentile; stools slightly abnormal; fair muscle tone and mass	Minimal accentuated bronchovascular markings; early emphysema
Mild (56-70)	15	May rest voluntarily during the day; tires easily after exertion; fair school attendance	Occasional cough; perhaps in morning upon rising; respirations slightly elevated; mild emphysema; coarse breath sounds; rarely localized rales; early clubbing	Weight and height above 3rd percentile; stools usually abnormal; large, and poorly formed; very little, if any, abdominal distention; poor muscle tone with reduced muscle mass	Mild emphysema with patchy atalectasis; increased bronchovascular markings
Moderate (41-55)	10	Home teacher, dyspneic after short walk; rests a great deal	Frequent cough, usually productive; chest retraction; moderate emphysema; may have chest deformity; rales usually present; clubbing 2 to 3+	Weight and height below 3rd percentile; poorly formed, bulky, fatty, offensive stools; flabby muscles and reduced mass; abdominal distention mild to moderate	Moderate emphysema with widespread areas of atalectasis superimposed areas of infection; minimal bronchial changes
Severe (40 or below)	5	Orthopneic, confined to bed or chair	Severe coughing spells; tachypnea with tachycardia and extensive pulmonary changes; may show signs of right-sided cardiac failure; clubbing 3 to 4+	Malnutrition marked; large protuberant abdomen; rectal prolapse, large, foul, frequent, fatty movements	Extensive changes with pulmonary obstructive phenomena and infective labor atalectasis and bronchiectasis

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