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A COMPARATIVE STUDY OF SEVERAL PSYCHOLOGICAL ASPECTS OF ADOLESCENTS WITH AND WITHOUT CYSTIC FIBROSIS

By

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ABSTRACT

A COMPARATIVE STUDY OF SEVERAL
PSYCHOLOGICAL ASPECTS OF ADOLESCENTS
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By

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Adolescence is considered a transition from childhood to adulthood, but for the adolescent with a life-threatening illness, the move towards separation and the enlarging scope of the future are shaded by the threat of premature death. While all illnesses impose psychological demands on the developing adolescent, the demands of cystic fibrosis, an inherited chronic disorder with an ultimately fatal outcome, are uniquely severe. This study attempted to understand how adolescents with cystic fibrosis, taking into account the special parameters of their lives, have "reconciled" their illness with particular aspects of adolescence. Twenty adolescents with cystic fibrosis and 20 adolescents without illness were compared on measures of future time perspective, separation anxiety, and coping and defense. It was hypothesized that adolescents with cystic fibrosis would be more attached, more defended on ego measures, and would exhibit less dense, coherent and extended future time perspectives than their well counterparts. Among the cystic fibrosis group, a number of additional variables, including the severity of illness, knowledge about the disease, and the divergence between self and doctor ratings of illness, were explored. It was found that the adolescent with cystic fibrosis is more defended, using more poorly integrated patterns of defense, than his well counterpart; his future is not

less dense or coherent, but he does not project himself as far into the future; and he is neither more attached nor less individuated. Among the adolescents with cystic fibrosis, males who know more about their disease are more coping; males who are more attached are less coping; and attached males have less dense and extended future time perspectives. Also, the less divergence between the adolescent's rating of his health and the doctor's rating, the more coping the adolescent. The importance of this area of research comes not only from the continually increasing life span of children with cystic fibrosis, but also from the increasingly prolonged life expectancy associated with many types of life-threatening pediatric diseases. Based on the findings, recommendations for further research, as well as treatment implications for health care providers, were discussed.

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CHAPTER I

INTRODUCTION

Adolescence is typically considered a period of transition from childhood to adulthood. The world of the adolescent becomes fundamentally different from the world of the child. Encouraged by advances in cognitive development, able to reason and think abstractly, to comprehend the meaning of such words as infinity, and to think in propositional terms, "if..then" (Inhelder and Piaget, 1958), the adolescent begins to imagine new persons and scenarios beyond his own family and immediate experiences, to conceive, anticipate and plan for a hypothetical, as yet unknown future, and to connect the realities of his present experiences with these wishes, hopes and future possibilities. Drawn to this new world of possibilities, attachments and allegiances begin to shift from parents and siblings to persons outside the family. No longer able to define himself solely in relation to his immediate, concrete world, his growing identity must now embrace not only the past and present, but a sense of himself in the future. Together, this emergent sense of identity, along with the capacity to conceive of a hypothetical world, lead to a beginning perception of his entire life span and an effort to bridge the past, present and future (Cottle, 1974). Thus, the consolidation of a stable and continuous identity, the enlarging scope of time and world through the anticipation of future events and persons, and the move towards separation and individuation, are intimately linked during adolescence.

For the adolescent with a life-threatening illness, the developmental tasks of adolescence are much more complex. For this youngster,

the ever-present threat of losing his future challenges this beginning sense of self-continuity; indeed, his entire identity may be threatened since this identity is linked with who-he-will-be in the near future (Kastenbaum, 1976). The move towards separation and the enlarging scope of the future and time are shaded by the threat of premature death.

While all illnesses impose both physical and psychological demands on the developing adolescent, the demands of cystic fibrosis are uniquely severe. An inherited chronic disorder with an ultimately fatal outcome, because of abnormally viscid secretions of exocrine glands, serious respiratory and digestive symptoms are recurrent and progressively more life-endangering. Treatment involves daily medication, careful attention to diet, postural drainage procedures, and in some instances, repeated hospitalizations. In addition to the extraordinary medical regimen - which usually entails daily help from parents or caretakers - a child with cystic fibrosis lives with the knowledge of a dramatically shortened life span. The continual dependence on others for daily care, even through adolescence, and the knowledge of an abbreviated future, must influence the way the developmental task of separation is managed, and the way the future is perceived and organized. This study investigated this claim. It sought to discover how the developmental presses of adolescence and the disease of cystic fibrosis were reconciled by a group of adolescents with cystic fibrosis. In addition to providing a descriptive look at how the adolescents shaped their futures, it also attempted to look at the adaptive solutions used by these youngsters in traversing their adolescence. The importance of this area of research

comes from the continually increasing life span of children with cystic fibrosis, as well as the prolonged life expectancy associated with many types of life-threatening pediatric diseases (Kellerman et al., 1980). While cystic fibrosis used to be a disease fatal in infancy or early childhood, with antibiotics and an increasing understanding of its pathophysiology, persons with cystic fibrosis on the average now live into their middle adolescence, many living well into their adult years. It was hoped that this research would be helpful to professionals working with adolescents who have cystic fibrosis; it was also hoped that this study would contribute to the more general area of pediatric illness and the impact of disease on the adolescent individual.

CHAPTER II

REVIEW OF THE LITERATURE

Attachment and Individuation

Adolescence

Although adolescence is viewed as a sanctioned intermediary period between childhood and adulthood, it has previously been studied primarily within the context of dysfunctional behavior. In the early psychoanalytic literature, theorists noted that adolescent behavior often resembled psychopathological states, and the period of adolescence was viewed as a stage of developmental disturbance (Freud, 1958). Writing within this theoretical perspective, Blos (1962) described adolescence as the second stage of individuation (the first stage occurring at about eighteen months of age), precipitated by a resurgence of infantile instinctual drives.

With the growth of both ego and developmental psychology, both of which emphasized mastery and competence, there was increasing interest in the behavior of adolescence as it reflected normative developmental tasks. Theory began to reflect this new perspective. Erikson (1963) viewed the consolidation of ego identity as the primary task of adolescence. The consolidation of an identity is accompanied by the issue of separating from one's family of origin. Other theorists describe achieving mastery over one's impulses and the development of love relationships as two more important tasks of adolescence (Lewis, 1973; Silber at al., 1961).

In the area of cognition, the development of formal operational thought is an important contributor to an adolescent's growing autonomy

by allowing him alternatives and hypothetical others. The adolescent begins to reason abstractly from hypotheses independent of concrete reality, and is able to imagine persons and scenarios that are not tied to the immediate reality of his already-defined spheres of persons and activities. Thus, cognitive development in adolescence, which provides the ability to conceive, anticipate and plan for a hypothetical future, is intimately tied to issues of autonomy and separation.

Separation as a Gradual Process of Childhood

Though the task of establishing oneself as an autonomous and separate person is typically thought of as one of the primary developmental tasks of adolescence, one can see how the task of separation is a gradual and evolutionary one, manifesting itself in physical, social and psychological ways at each stage of growth through increasing differentiation and individuation.

And one cannot adequately study the concept of separation without also studying its close counterpart, attachment. The ability to separate and the form it takes is clearly dependent on this antecedent variable. Bowlby (1973) was one of the early, major contributors to this area of study. He set forth three developmental propositions which he considered important to the understanding of attachment. The first states that when an individual is confident that an attachment figure will be available when needed he is less prone to intense and chronic fear. Secondly, confidence in the responsiveness and accessibility of these attachment figures is gradually built up over time, beginning with infancy, and remains with little change throughout the rest of one's life. And thirdly, these expectations are a result of actual early experience.

Other theorists stress the importance of early attachment behavior in subsequent personality development. Benedek (1956) maintains that confidence in early attachment figures is an important prerequisite to self-regulation during periods of life when no direct support is available and one must rely on one's own inner support. Mahler (1967), along with Erikson, believes that trust is established in infancy and early childhood through consistent and reliable mothering.

Implicit is the notion that a capacity for self-reliance and independence grows out of an earlier, safe dependency on others. According to Erikson (1968), the infant's first "social achievement" is his ability to let mother out of sight without excessive panic or rage, this the underpinning of an inner consistency and object constancy, "the recognition that there is an inner population of remembered and anticipated sensations and images which are firmly correlated with the outer population of familiar and predictable things and people." (Erikson, 1968)

During the stages of rapid muscular maturation and initial ambulatory excursions, the child learns to both hold and to let go, to explore and manipulate the things around him. Through a slow process of enculturation, the child learns to observe, imitate and finally to internalize tools and behavior which further a sense of independence and mastery over the environment. The child begins to invest himself in relationships outside the immediate family.

While attachment and separation are processes that begin at birth, they become characteristically different during adolescence where primary attachments and allegiances begin to shift from parents and

siblings to persons outside the family group. Adolescent separation implies a previous history of early attachment and gradual differentiation, and, within Erikson's schema, reflects the consolidation of the ego.

The variables of separation and attachment, then, are inextricably connected. In his term, "autonomy-relatedness," which describes the capacity for both independent behavior and the maintenance of parental ties, Bowlby (1973) emphasizes this connection: "Based on early separation experiences and availability and responsivity of attachment figures, the individual develops a working model of object relations which concerns his need for relatedness and separateness." Similarly, Schaffer (1968) says that "the optimum toward general personality development appears to be a balance (within wide limits) between identification and continuing object relations."

The above theorists suggest that a balance between the drive for attachment and the drive towards individuation leads to the healthy development of the adolescent.

Attachment and Individuation: Empirical Studies

Research in the area of adolescent development suggests that separating from one's family of origin and social competence in the extrafamilial environment during adolescence requires substantial, continuing involvement with family members, particularly parents. Douvan and Adelson (1966) maintain there is a curvilinear relationship between the development of autonomy and the extent of parental involvement. Studying the "departure" of the adolescent from the family in large samples of adolescents, they concluded that autonomy is best developed at a moderate level of parental involvement, whereas

too little or too much involvement disturbs the development of autonomy.

Other than objective questionnaires developed during the 30's and 40's, there was little research done on the issue of separation as a normative, developmental task until the 1960's when a group of researchers from the National Institute of Mental Health (Murphey et al., 1963), deriving their theoretical base from Bowlby's work, began investigating how adolescents managed the transition from high school to college.

Adolescents were grouped according to their relative position on two dimensions, autonomy and relatedness. Autonomy was defined as the ability to make responsible and separate choices, and by reported feelings of being a separate person rather than an extension of others. Relatedness was defined as a positive relationship with parents based on mutual interest, communication and emotional closeness. The choice of these two factors reflects the researcher's theoretical indebtedness to Bowlby's concept of autonomy-relatedness.

It was found that while parents of the high autonomy and high relatedness group encouraged autonomous behavior, they allowed a greater range of experimentation (within a set of family guidelines), they also exhibited a congruence between their beliefs and actions, and were available as models of autonomous persons with whom the students could readily identify. Those students low on both autonomy and relatedness had difficulty rejecting outside influences in making choices, came home less often than the first group, and kept an emotional distance through detachment or negativism. Their parents exhibited greater discrepancies between values and behavior and had a more difficult time accepting the

students as young adults rather than dependent children; importantly, they expressed a lack of confidence in their children's abilities to succeed away from home. Parents of students who were highly autonomous but only moderately related were similar to the high autonomy and high relatedness group with one exception. Parents assigned their children more restricted and less flexible roles and when the children broke away in an attempt at autonomous action, conflicts ensued. These students often reported feeling more "at home" in college than with their families.

This study is important in that it supports the theoretical literature which suggests that a balance between autonomy and relatedness leads to the greatest psychosocial competence in adolescence.

A number of other studies have explored the broad relationships between parents and children and indices of social adjustment outside the family. In general, these studies suggest that psychosocial competence is best developed in families where parents, in supportive and cooperative marital relationships, express warmth and interest in their child's activities and encourage active participation within the family in making family decisions. At the same time, these parents express support for their independent, autonomous behavior and involvement with peers outside the family. These findings support the empirical notion of a balance between autonomy and relatedness (Douvan and Adelson, 1966; Bowlby, 1973; Murphey et al., 1963; Offer and Offer, 1975).

Autonomy and the Concept of Time

While the previous sections have explored the issues of attachment and separation, another important aspect of adolescence which is intimately connected with issues of separation and autonomy, and salient to

the study of adolescents with cystic fibrosis, is the notion of the time concept. The consolidation of a stable and continuous identity is linked to the acquisition of a stable and continuous notion of time: "The young person, in order to experience wholeness and self-continuity, must feel a progressive continuity between that which he has come to be during the long years of childhood and that which he promises to become in the anticipated future (Cottle and Klineberg, 1974)."

There is no evidence to suggest that the development of temporal experience parallels the evolution of the self or ego (Rabin, 1978). Because the task of individuation and separation is connected with the enlarging scope of time through the anticipation of future events and persons, the structuring of time and the characteristics and mode of separation might be expected to be related. The development of the time concept (and more specifically, future time perspective) and its relationship to the general development of the child will be explored in the following section.

Future Time Perspective

Developmental View of Future Time Perspective: A Theoretical Exploration

The connections between developmental stages of personality and the concomitant unfolding of temporal experience have been explored by others (Wallace and Rabin, 1960). The concept of time is a process that begins in a primitive, rudimentary way in infancy through the alternating experiences of frustration and satisfaction around feeding, and continues to develop through the play activities of the preschooler. Experience in the larger world (outside the family) and the acquisition of symbolic thought through language and speech, give

increasing breadth to the future. But, according to Piaget, who labeled stages of development according to their corresponding cognitive levels, the pre-schooler or pre-operational child is, as yet, only able to deal with reality as it is seen (1952). In the following stage of concrete thinking (at about eleven or twelve), the child is able to draw inferences from the actual to the potential. As his understanding of the logic of classes and relations emerge, he is able to organize his experience into an integrated set of cognitive operations which give consistency to the world. He is not, however, able to apply the same logic to verbal propositions which are devoid of concrete content. And a pre-adolescent or concrete stage child's cognitive capacities do not yet let him comprehend the psychologically distant, abstract or hypothetical: "A child is unlikely as yet to integrate distant anticipations of his adult years into an overarching sense of identity or an awareness of his life as a whole" (Lewin, 1935). A preadolescent might not yet distinguish between realistic expectations and unrealizable wish-fulfilling fantasies: "The ideal goals and real goals for the future are not much distinguished and this future has the fluid character of the level of unreality." (Lewin, 1935)

Thus, while the preschool child is concerned with the present, the preadolescent inhabits the present and the relatively near future. A child's projected adult years, however, remain unconnected with his present, although they are available for the projection of wish-fulfilling fantasies and often offer a possibility of escape from the frustrations of the present. Wallace and Rabin (1960), in their review of the published research concerned with temporal experience,

report that "the time concept, with ever-widening past and future references, continues to develop through the thirteenth or fourteenth year when the adult concept /of time/ first emerges. At that time, the notion of continuity of time and its relatively accurate estimation are reached." With the acquisition of formal operations, the adolescent now conceives of the years of adulthood with a far greater sense of reality than when the real future was limited to concrete extensions of the present situation or to events already experienced (Cottle and Klineberg, 1974). The adolescent is now able to conceive of time in abstract terms and the future is open to reasonable expectation and planning.

"While the child deals largely with the present, with the here and now, the adolescent extends his conceptual range to the hypothetical, the future and the spatially remote." (Flavell, 1963) With these new conceptual abilities, he is more likely to sense the connections between his present and future, and the span of temporal integration may extend dramatically farther into the distant future (Cottle and Klineberg, 1974). Says Inhelder and Piaget (1958):

> The connection indicated by the words, "if..then" (inferential implication) links a required logical consequence to an assertion whose truth is merely a possibility. This synthesis of deductive necessity and possibility characterizes the use of possibility in formal thought as opposed to possibility-as-an-extension-of-the-actual-situation in concrete thought and to unregulated possibilities in imaginative fictions.

Time is now viewed as an abstract continuum encompassing all moments in an irreversible succession.

In summary, there is a broad theoretical base for believing that adolescence brings a significant change in the way an adolescent envisions his future: "Images of future experiences are now more securely linked with the present. Where wish-fulfilling fantasies once reigned

supreme reality now intervenes." (Cottle and Klineberg, 1974) This notion is supported in the empirical literature.

Empirical Studies on the Time Concept

The available data are generally consistent with the notion that the distant future assumes a new reality in adolescence. Research demonstrates that notions of the future and how they are integrated into the present correspond to particular developmental stages, with different findings for children and adolescents.

Farnham-Diggory (1966) asked children, age seven to sixteen, to indicate on a 197 millimeter line how far away various future times seemed to be. The subjective time periods ranged between three hours and eighty years from the present. She found that distances marked on the line were significantly related to the age of the child; the younger the child, the farther away the future seemed.

Davids and Parenti (1958) collected story-completions from boys age seven to thirteen. They found that the more well-adjusted boys (as evidenced by stories rated by psychologists for optimism, stability of friendship and personal happiness) told stories in which the action took place in the present.

Klineberg (1967) conducted a study which demonstrated results similar to those of Davids and Parenti. He tested two groups of French boys, age ten to twelve. One group consisted of boys enrolled in special schools for maladjusted children, the other group was comprised of 23 boys of the same age and grade levels attending a private suburban Paris school. There were four measures of the child's orientation toward the future: 1) Each boy told stories based on two TAT cards and indicated the amount of time that passed between the beginning and

end of the action they described; 2) they were asked to recount ten different things they had thought or spoken about during the preceding week, questioned about what they thought or spoke about these events and each event given a temporal placement (past, present, and future); 3) they were then asked to list as many different things they thought might happen to them during the rest of their lives and to indicate how old they thought they would be when these events occurred; 4) finally, they were given fourteen life experiences and asked to guess when each of these events might occur.

There were no significant differences between groups in the number of anticipated future events nor in how far they projected themselves into the future. However, when asked to guess at what point the fourteen given events would occur, the more maladjusted adolescents made median estimates extending significantly farther into the future, and their TAT stories encompassed longer spans of time than the stories of normal boys. Specifically, the maladjusted boys more often told stories with optimistic endings, whereas the normal children more often merely described the situation present on the card with no discernible outcome. Says Klineberg: "Unlike their more maladjusted peers, these children seemed perfectly willing to leave all the action in the present."

Klineberg (1967) then interviewed two groups of French adolescents, age thirteen to sixteen. One group consisted of adolescents attending a private school for boys with serious academic difficulties, the other group attended a regular school. They were given the same tasks as the preadolescent boys from the first study. In comparison with the normal young men of the same age, the maladjusted adolescents listed

significantly fewer and less distant future events. Moreover, in response to both TAT cards, the maladjusted boys told stories that encompassed a significantly shorter period of time.

Comparing the results from the two studies, the stories told by normal adolescents were strikingly reminiscent of those told by the maladjusted children. That is, normal adolescents and maladjusted children both told stories with optimistic endings and long prospective time spans. In contrast, the maladjusted adolescents generally told pessimistic stories within a relatively narrow time frame; like normal children, they were less oriented towards distant future events.

These studies suggest that for unhappy or maladjusted children, the future is available for projecting wish-fulfilling (optimistic) fantasies. But because the future has assumed a tangible reality during adolescence, it is less available as a means for fantasied escape, its unpleasant realities to be avoided, the unhappy adolescent confined to the present (Cottle and Klineberg, 1974). These results confirm the theoretical notions presented earlier: there is a greater future orientation among the more maladjusted preadolescent children, but by middle adolescence, the more unhappy and maladjusted the adolescent, the less oriented he is likely to be towards the distant future.

However, in a study of time perspective in normal adolescents, Kastenbaum (1976) found that while most of the adolescents did direct their thoughts to the future, almost everything important in life was "just up the road a piece." The second half of their life span was described as almost empty, with little thought regarding the fourth of fifth decades or beyond. While the future was perceived and

experienced as immediate, the past seemed to be "blanked out." Kastenbaum observed that these adolescents felt uneasy about being asked to think about where they had been, moving hurridly from "now" to "next" with little knowlege of what was to follow "next." While this study does not contradict the previous data, it might amend it: while normal adolescents may be future-oriented, Kastenbaum suggests this future does not extend very far in time.

There is also evidence to suggest that within the same age groups, there are major differences in time perspective, not only in how much individuals think of the future, but how much future they consider themselves to have. In a study by Sabatini and Kastenbaum (1973), a group of college students were asked to compose their own death certificates. There were marked differences among the group studied with regard to the amount of time perceived to be remaining in their lives. The authors concluded: "Just knowing that a person was of the current college generation would not enable us to predict reliably that he or she envisioned death to be many decades away."

Thus, while the acquisition of the concept of temporality, and specifically, future time perspective, is related to developmental stages, there are also other factors which influence the development and experiencing of future time perspective. Some of these other factors will be explored in the following sections.

Other Factors Affecting Future Time Perspective

Wohlford (1966) asked college students to describe in detail an unpleasant experience they thought would probably happen to them in the future. Subsequently, when asked to list twenty topics they had recently thought or spoken about (compared with twenty other events

listed before they were forced to envision an unpleasant future), they mentioned significantly fewer future and more past events. Wohlford concluded that when an individual confronts the possibility of something unpleasant, he tends to stop thinking about the future, turning instead to the present or the past where events are less threatening if only because they have already occurred.

Eson and Greenfield (1962) asked males and females, age 10 to 65, to list the things they had recently thought about and to indicate their feelings about them. Those items referring to future events were particularly likely to be rated as pleasant. The authors concluded: "We rarely expect the worst from the future, and when we do, we tend to think about other things."

Osgood (1962) suggests our time span contracts to the present moment when we are emotionally driven or absorbed. Cottle and Klineberg (1974) suggest there is a curvilinear relationship between anxiety and temporal orientation. The onset of anxiety itself presupposes the anticipation of the future. Research suggests that moderate anxiety may facilitate the expansion of the dimensions of integrated time as a person searches for ways to control the future he envisions, while excessive anxiety may contribute to the dissolution of temporal integration and expansion (Cottle and Klineberg, 1974).

Experimental studies suggest that psychopathological states influence temporal experience. Dilling and Rabin (1967) found that schizophrenics exhibited less coherence in the way they structured their future and depressives exhibited a more constricted sense of time (both past and present) than either schizophrenics or normals.

Depressives also tended to overestimate time: "Every hour seems like a year to me."

Research suggests that an undesirable future will be acknowledged if a person believes there is something he may do to change it. If this unpleasant future seems unavoidable, a person may maintain a relatively restricted time orientation which then operates as a defensive strategy, offering protection from the anticipation of an unpleasant future:

> Images of that unhappy future may then be actively excluded from consciousness and relegated to a realm of pure subjectivity, safely unconnected with current realities. Under these circumstances, the span of future time that will be integrated with conceptions of the past and the present may be limited to those relatively short range events that a person feels she or he can control. (Cottle and Klineberg, 1974, p. 23)

Thus, attending only to the present can serve as a defense against unavoidable pain.

Future Time Perspective, Individuation and Death

One unavoidable reality in every individual's future is death. "Thoughts of time and death have a natural affinity for each other. What is left of our lives is in the future, and death also resides in the future." (Kastenbaum, 1976)

Using a group of college students, Dickstein and Blatt (1966) studied the relationship between two measures of future time perspective and the preoccupation with death. The questions about death were straightforward: "I think about my own death more than once a week, once a week, once a month, once a year." Futurity measures included story completions from given story roots and the Picture Arrangement subtest from the WAIS which is often used as a measure of the capacity to anticipate and organize future events. They found

that those who exhibited a high manifest concern about death had more restricted projections into the future; those with low manifest death concern showed significantly greater future extension. Since this was a correlational study, it does not give any indication about directionality, that is, it doesn't determine whether concern about death affects futurity or whether futurity affects concerns about death.

Kastenbaum (1976) suggests that as the adolescent moves towards individuation, he or she will experience a greater concern about death. Hypothesizing that a heightened awareness of oneself as an individual heighten's one's concern about death, he says the following:

> ...what does it mean to experience oneself as an individual, especially when the experience is of recent vintage? It means to experience oneself as alone. To be an individual and to be alone is also to be in a new kind of relation to death...the acute perception of individuality-aloneness seems to invite a sharpened sense of mortality. Although he has achieved a higher level of integration than he possessed as a child, the adolescent or young adult has not eluded the relationship between self-constancy and the prospect of death. (p. 410)

Thus, as described earlier, the move towards individuation in adolescence is intimately connected with the notion of time, and the notion of time,more specifically, future time perspective, is linked to death. These interrelationships are present for all adolescents, but for adolescents with cystic fibrosis, these concerns present themselves earlier and more bluntly.

The next section will focus on the specific concerns of adolescents with cystic fibrosis.

Cystic Fibrosis

An Introduction

Cystic fibrosis is unique in that it is both a chronic and fatal disease. This contrasts with other diseases of childhood, juvenile diabetes, for example, which is chronic but usually not fatal, or leukemia, which has a fatal outcome after a shorter course. Because no known defect accounts for all the pathophysiologic manifestations in cystic fibrosis, strictly speaking, cystic fibrosis must as yet be considered a syndrome rather than a disease (Wood et al., 1976).

Cystic fibrosis is considered an inborn error of metabolism genetically transmitted as an autosomal recessive trait. It is the most frequent lethal genetic syndrome in Caucasian children, occurring in approximately one in every one thousand two hundred live births. Five percent of most white populations are calculated to be carriers of the cystic fibrosis gene. Cystic fibrosis is characterized by abnormally viscid secretions of the exocrine glands and manifested to various degrees in the lungs, GI tract, sweat glands and sexual organs and resulting in obstructions of organ passages. While cystic fibrosis is often manifested and diagnosed at birth by a positive sweat chloride test, in rare instances, diagnosis is not made until adolescence. Cystic fibrosis produces infertility in most males, but other than a delay in the onset of menarche (Wood et al., 1976), it does not affect the female reproductive system. At present, cystic fibrosis has no cure, with symptoms becoming progressively more severe and often necessitating repeated hospitalizations. Although there are varying degrees of severity and various ways the disease is manifested, chronic obstructive lung disease and infections secondary to these obstructions

are typically responsible for the eventual outcome of the disease. Treatments, which are daily, time-consuming and offer only symptomatic relief, involve antibiotics, multivitamins, postural drainage and percussion, and a controlled diet.

When cystic fibrosis was initially recognized as a discrete disease entity or syndrome in 1938, 85 percent of all infants diagnosed with cystic fiborsis died by the age of two (Shwachman et al., 1965). In their 1955 chapter on Mucoviscidosis in the Advances of Pediatrics, Shwachman and Leubner point out that "only a rare patient survives to age ten." In a study in Great Britain in 1974, 72 percent of children with cystic fibrosis were found to live until age 12, and 45 percent lived to the age of 20 (Mearns, 1974). Presently, the life span for individuals with cystic fibrosis increases on the average of one year each year (GAP Conference, 1980). Thus, although cystic fibrosis used to be a disease fatal in infancy or early childhood, individuals with cystic fibrosis now live, on the average, into their middle adolescence, with many living well into their adult years. Lefebvre (1973) describes the difficulties in cystic fibrosis: "As long as a precise etiology and prevention of cystic fibrosis eludes us, the treatment of this illness remains chiefly palliative and based upon meticulous pulmonary hygiene which requires tremendous expenditures of time and energy pursued over an indeterminate period that may seem endless."

A Developmental Perspective of Cystic Fibrosis From Infancy to Adolescence

Just as an earlier section explored the issues of autonomy and separation and the consolidation of a time perspective from a normative, developmental perspective, it would be useful at this point to

present a developmental view of the child with cystic fibrosis. Highlighting the most significant aspects of development as they might later relate to adolescence, this cannot be a complete developmental review since part of the task of this study is to gain a greater understanding of the developmental course of a child with cystic fibrosis through his adolescence.

Because of its varied presentation, cystic fibrosis is a disease that does not always receive early diagnosis. In infancy, cystic fibrosis can be confused with other disorders and go unrecognized for long periods of time. During the early stages of development, cystic fibrosis can dramatically affect the early attachment of mother and infant through problems around the feeding process. Eighty-four percent of undiagnosed infants were characterized as vocarious feeders who nonetheless failed to thrive during the first three months of life (McCollum and Gibson, 1970). The unsatisfied infants were fussy and difficult to comfort. In addition to difficulties around feeding, foul smelling stools, an intrusive and constant cough and the rigors of daily management can complicate the attachment process.

Farkas (1973) studied the severity of a child's illness and its effect on his psychological functioning and the functioning of other family members. She found that mothers of children with mild presentations of cystic fibrosis (as defined in the study) reported more feeding problems and insecurity about their child's failure to grow than those whose children were in the terminal stages. In the mild cystic fibrosis group, the mean age at diagnosis was 37.2 months compared with the terminal group where mean age at diagnosis was 26.6 months. Farkas suggests that the longer period where symptoms

remained undiagnosed may have allowed more time for the mother to develop feelings of insecurity about the growth of her infant.

With the school age child, separation from the family acquires a new, visible reality as the child leaves home daily to go to school. Physical differences between children with cystic fibrosis and normal children can cause social estrangement, and the accompanying physical symptoms of cystic fibrosis may place the child in socially embarrassing situations. McCollum and Gibson (1970), in studying 65 families with a child with cystic fibrosis, found that 44 percent of the children studied had school adjustment problems (day dreaming, inattentiveness, restlessness, disruptive classroom behavior). Forty-seven percent of parents in this study indicated they permitted their children less independence than if their child were healthy.

While the impact of cystic fibrosis on the entire family is not the focus of this study, there are research findings in this area that are pertinent to the area of individuation and separation in adolescence. Most studies of the family with a child with cystic fibrosis have indicated considerable marital discord (Lawler et al., 1966; Turk, 1964). Lawler found intrapsychic and interpersonal conflicts among the parents of all the cases he studied. Mothers were described as clinically depressed, often showing hostility toward the child with cystic fibrosis, and fathers were typically described as physically and emotionally absent. Marital problems were suggested by the finding that six of the eleven couples studied had considered separation and three couples had no sexual relationship. Since this study was without experimental control, however, these findings can only be suggestive.

Literature relating to other problems of childhood would suggest that the presence of major interpersonal conflicts between the parents will clearly have an effect on the normal developmental course of the child (Satir, 1967). The school phobic child, for instance, is often afraid to attend school because of the wavering foundation, home, he is leaving behind. (Weiner, 1970) Research on families which suggest that the child with cystic fibrosis often develops an especially close relationship with his mother, with father being more remote (Lefebvre, 1973; Tropaner et al., 1970; Lawler et al., 1966), might indicate that difficulties of separation will be exacerbated by this family "skew." (Lidz, 1973)

In Lefebvre's (1973) study on adolescents with cystic fibrosis, a large proportion of patients described themselves as being very dependent upon their families. Only three patients lived alone, while the majority were still living with their parents. Two thirds of all the patients felt ambivalent about their strong dependency needs but were anxious at the thought of living alone. While these adolescents and young adults described their parents (and more specifically, mothers) as overprotective, overanxious and guilt-ridden, a majority described themselves as very dependent upon their parents.

Lefebvre eloquently summarizes the position of the adolescent and young adult with cystic fibrosis:

> The teenager and young adult with cystic fibrosis experiences severe difficulties in separating from an often overprotective and occasionally rejecting family upon whom he feels unusually dependent because of time-consuming, expensive treatments. Often anxious and depressed, he has doubts about his identity and worth as a student, worker, friend and sexual mate, and is hesistant to engage himself in an intimate relationship with a member of the opposite sex. His understanding of cystic fibrosis is frequently incomplete, especially in terms of the genetic implications of his illness, while he is planning, in most cases

> to have his own children. Riddled with doubts about himself and fears of the future, he is unable to find anyone to completely confide in and is left alone with his anxieties (p. 36).

The Impact of Cystic Fibrosis on the Psychological Functioning of the Child

While there are descriptive studies which discuss cystic fibrosis and its psychological implications for adolescence(Teicher, 1968; Grossman, 1975; Palmer, 1977; Lefebvre, 1973), and while there are research studies that include adolescents as part of their sample group (Lawler et al., 1966; Meyerowitz and Kaplan, 1967; Tropauer et al., 1970; Farkas, 1973; Gayton et al., 1977), until recently, there have been relatively few research studies examining the impact of cystic fibrosis on the adolescent or young adult with his or her particular developmental concerns. Many studies examined the broader perspective of the impact of cystic fibrosis on the psychological functioning of the child, often including adolescents as part of their samples.

Data is equivocal with regards to the effects of cystic fibrosis on the psychological functioning and development of the child. Results from some studies suggest that as a group, children with cystic fibrosis experience considerable psychological disturbance.

Lawler et al. (1966), in an uncontrolled study, administered psychological test batteries to 11 children with cystic fibrosis whose ages ranged from five to 19 years of age. Pre-schoolers were administered the Stanford Binet and CAT, school-age children were administered the WISC, Rorschach and Schnoell Reading Test, and the two adolescents, ages 17 and 19, were given the WAIS and the Rorschach.

From these tests and from psychiatric interviews, results suggested that children across ages with cystic fibrosis had marked anxiety, depressive trends and a preoccupation with death.

Tropauer et al. (1970) found that while all children expressed a preoccupation with death and disability, this was especially true of adolescents. In this descriptive study where 20 children with cystic fibrosis age five through 20 were studied along with their mothers, results showed that the concerns and anxieties expressed by the children were in part a reflection of their specific developmental stage. Again, no comparison group was used.

Tropauer found that the young child frequently complained about interruptions of play, his limited diet, and being unable to keep up with others in sports and games. A few expressed concerns as to how they would get treatments when they grew up and moved away from home. The adolescents were more preoccupied with disability and death. They worried about the way their social life was restricted and were concerned about being different from their peers. Some were particularly concerned about their smaller stature.

Tropauer concluded that the younger child, with limitations in his abstract thinking, is more concerned with separation from his parents on whom he is totally dependent, and less concerned with death, which is a more central concern for the adolescent.

In exploring occupational plans, the choices of professions seemed to reflect the process of identification, where passive, painful experiences are converted into active roles in an attempt to relieve anxiety. Future ambitions included "helping people" in professions such as clinical medicine, medical research, nursing, or,

in one case, life-saving. One little girl responded to a question about future ambitions by saying she hoped "to become a teenager."

On an abbreviated House-Tree-Person technique, the children's drawings reflected anxiety, insecurity and feelings of inadequacy as evidenced by the distorted body images in over 70% of the drawings.

Spock and Stedman (1966) gave 21 children a battery of psychological tests including the Peabody Picture Vocabulary Test, the Goodenough Draw-A-Person Test, and selected Bender Gestalt cards. As in the Tropauer study, the projective drawings showed feelings of inadequacy, high anxiety and need for strength.

Some studies contradict the findings reported above which suggest that children of all ages with cystic fibrosis exhibit considerable intrapsychic conflict. Gayton et al. (1977) did not find an increase in emotional disturbance in children with cystic fibrosis. He studied 23 children age five to 18. These children were tested with the Piers-Harris Self-Concept Scale, the Missouri Children's Pictures Series and the Holtzman Inkblot Test. (Older children in the study were administered the Tennessee Self-Concept Scale because it is a more appropriate measure of self-perception in the adolescent).

The total self-concept score for patients with cystic fibrosis was higher than Pier's data for normal children (1969) which indicated a perceived state of well-being. The self-concept scales are measures of self-perception and therefore more subject to persons responding in socially desirable ways. Since studies of children with serious illnesses would suggest that denial is a primary defense mechanism (Mattsson, 1972), high self-concept scores may reflect a defensive strategy of denial rather than an accurate reflection of well-being.

Another study by Tavormina (1976) investigated the psychological functioning of groups of children with diabetes, asthma, cystic fibrosis and hearing impairment on a battery of standardized personality instruments in order to test the hypothesis that chronically ill children are especially vulnerable to psychopathology, Tavormina found that with few exceptions (for instance, children with cystic fibrosis were more dependent, less mature and voiced more problems with intellectual and school status and their physical appearance), results on the tests demonstrated the normalcy of these children. (Tavormina also included the Piers-Harris Self-Concept Scale in this study, along with the Nowicki-Strickland Locus of Control Scale for Children).

In contrast to the above studies, Farkas (1973) divided her sample of cystic fibrosis subjects into two groups, fatal versus non-fatal prognosis, or good versus poor current physical functioning. The designation of severity of illness was made by the patient's physician. She was interested in finding out whether it was necessary for the child to be obviously physically ill for the individual and family to accept and adapt to the child's illness, or if merely the knowledge of the diagnosis, along with clinic visits and home care of outwardly healthy-looking children were sufficient. Futterman (1970) had observed earlier that during periods of remission, denial is strong and the return of symptoms is met with unanticipated shock.

Contrary to expectations, Farkas found no differences between the groups on measures of anxiety, guilt, depression, future time perspective, adjustment or openness in the families. Two of the older patients who came from families rated as maximally open in discussion

of the illness, and who had had numerous hospitalizations and been in contact with other children who had died from cystic fibrosis, both stated that "it was not until they had become very sick, in fact, close to death themselves in their late teens and early twenties that they had fully realized that they would be likely to die of cystic fibrosis at an early age. Both said they might have lived their lives differently had this realization come earlier. But one said he was glad not to have known about the severity of his disease; the other said she had talked from an early age about not living as long as other people, but this was an intellectual knowledge, different from an immediate confrontation with the possibility of dying. (Farkas, 1973)

Kulczycki, Robinson and Berg (1969) studied parents of children with cystic fibrosis at the time of diagnosis and found no relationship between the quality of the parents' adaptation to the illness and the severity of the child's illness.

Comparisons of results across these studies are difficult for a number of reasons. First, each study uses different measures, some studies using abbreviated measures, some more extensive batteries, projective tests, or a combination of objective and projective tests. Secondly, these studies often include broad age ranges of children and young adults and their conclusions attempt to address these various age groups as a uniform population. Thirdly and importantly, many of these studies do not include experimental controls or comparison groups, some using anecdotal observations or small samples.

The Psychological Effects of Cystic Fibrosis on Adolescents and Young Adults

Some of the descriptive and research studies that have explored the lives of adolescents and young adults with cystic fibrosis seem to suggest profound difficulties. Pinkerton (1969) observed that adolescents saw themselves as different from and inferior to their peers, and resented the dependency necessitated by the management of the disease. Patterson (1969) observed that adolescents worried about being unable to get a job because of their disease and were concerned about not being able to marry and have normal children.

In a descriptive study by Lafebvre (1973), 30 patients age 13 and over were interviewed to obtain a picture of global psychosocial functioning. Twenty-three of the 30 patients felt inferior to normal and described themselves as "trouble-makers, social outcasts and "ugly ducklings." One third said they were depressed all the time and one third had periods of despair during which they contemplated suicide through stopping treatments (four had stopped treatments for some period of time).

All patients demonstrated a high level of anxiety, particularly when discussing their future. While it was difficult to assess defense mechanisms within the interview situation, Lafebvre felt that most patients alternated between a protective use of denial, rationalization and reaction formation, and a reactive depression. Six seemed to exhibit a more sustained use of denial of their diagnosis (these patients mirroring their parents' attitudes) and this seemed to be reflected in the high proportion of patients who had an incomplete knowledge of cystic fibrosis.

While grades were represented by a normal distribution, most patients felt they weren't doing well, and this dissatisfaction seemed more related to general feelings of inadequacy. A few older patients commented on their feeling that they were "running out of time" which made it difficult to participate in school. One patient commented that any future she might build for herself would be a "quick-sand castle" which could crumble suddenly. Some students who had quit college study felt they should travel when they could. With what was described as a constant feeling of impending catastrophe, many felt that study was not important. Boyle et al. (1974) studied 27 patients age 13 to 30 by psychological testing (intellectual tests and full projectives) and psychiatric interview data reviewed by two psychiatrists. These patients were evaluated on performances at work and school, for the quality of their interpersonal relationships, interactions with family members, and styles of coping with illness. While these patients were competent in their daily routine, and with the majority doing well in school, Boyle found areas that were very problematic. In interviews, all the patients expressed dissatisfaction with their bodies, and on the Draw-A-Person, drawings were often juvenile, with 17 patients showing striking denial of sexual differentiation, male and female characters often being indistinguishable. For some patients who did not deny their sexuality, their pictures were exaggerated in proportion with very little correspondence to their own body.

The majority of patients felt isolated, half felt they had no close friends, and many felt they had been rejected by people when they tried to begin friendships, withdrawing into their relationship

to their mother. Seven of the 27 were married, however only one marriage was characterized as stable. One patient was getting a divorce and three patients said they often considered divorce.

Boyle noticed a difference in how the adolescents and young adults managed their future. The adolescents appeared very anxious when asked to talk about the disease. One third claimed to know only the name, cystic fibrosis, although they said it had been explained to them by physicians. However, projective testing indicated they knew a lot about their disease but tried to avoid talking about it: "You can't do anything about it and it isn't going to change my way of living." Boyle found that adolescents in their last years of high school often felt, "what's the use with regard to making decisions about the future." Young adults either avoided looking at the future or were preoccupied with the past. In contrast to the adolescents, they appeared less overtly anxious when cystic fibrosis was mentioned.

As in the studies examined earlier (Tropauer et al., 1970; Lawler et al., 1966), feelings about death were a major preoccupation of both adolescents and young adults, with patients using denial and avoidance as primary defense mechanisms to deal with their concerns.

While Landon et al. (1980) did find that males with cystic fibrosis perceived themselves as unhappy, they postulated a different basis for this unhappiness. They compared males and females with cystic fibrosis (ages 12 through 19) with otherwise healthy, short stature males who may also have had delayed puberty. All three groups were considerably below the mean height and weight percentiles and were delayed in sexual development as measured by Tanner stages.

On the Offer Self-Image Questionnaire which measures the adolescent's self-perception of his or her personal mastery of the

problems of adolescence, both groups of males, males with cystic fibrosis and short stature males, perceived themselves to be disturbed. The authors concluded: "Woven through studies is concern that the Damoclean sword of fatal illness has been a major impediment to the individual's ability to complete adolescence...It is entirely possible that the CF males are as upset about being short as about having cystic fibrosis!" Females, they suggest, are more able to disguise maturational delay through clothing. Thus, Landon et al. suggest that adjustment problems in adolescent males with cystic fibrosis may be a consequence of their growth retardation and pubertal delay rather than the "sword" of an early death.

Goldberg (1979) studied adolescents with cystic fibrosis who were compared with normal adolescents of the same age and educational standing on measures of vocational development and adjustment. They hypothesized that adolescents with cystic fibrosis would be less mature than healthy children on their educational and vocational planning for a career, and would have less knowledge of occupations and take less initiative in forming a vocational plan.

In the lower grades (seven through nine), adolescents with cystic fibrosis scored significantly lower than adolescents without illness on measures of educational plans and realism (defined as the ability to plan while bearing in mind one's limitations as well as environmental constraints). But they scored higher (although with the exception of the seventh grade, not significantly so) on the variables of work values, strength of commitment and degree of awareness and occupational requirements. In grades 10 through 12, adolescents with cystic fibrosis scored significantly higher on strength of

commitment and degree of awareness, and significantly lower on realism, educational and vocational plans.

Many of the adolescents with cystic fibrosis expressed an interest in entering one of the health professions (similar to the finding by Tropauer et al., 1970), and Goldberg attributed their high scores on awareness of occupational information and strong commitment as a reflection of their continuing involvement with the health care system and their close relationships with medical caregivers. For adolescents with cystic fibrosis, work was seen primarily as a way to gain personal satisfaction and secondarily as a way of earning income and supporting a family.

A Theory of Psychological Innoculation

The Goldberg study suggests that adolescents with cystic fibrosis do have strengths and might be able to better meet the demands of adolescence than implied by the findings of the previously discussed studies. And, there seems to be a growing body of empirical research which proposes that living with chronic illness leads to a process of "psychological innoculation," strengthening the individual's ability to cope with varying life events.

Straker and Kuttner (1980) found no difference between adolescents with cystic fibrosis (age 12 to 16) and well adolescents on measures of peer and family relationships, anxiety about death and the future, depression and locus of control. Adolescents with cystic fibrosis did score significantly higher on the measure of persecution.

Kellerman et al. (1980) found no differences between adolescents across varying groups of illness and well adolescents on measures of state-trait anxiety and self-esteem. Only adolescents with cystic

fibrosis and diabetes scored comparably with well adolescents on a measure of locus of control (exhibiting higher internal than external control), even though they were rated by their physicians as having shortened life expectancies. All other illness groups (adolescents with cancer, cardiologic disorders, renal syndromes, rheumatologic disorders) were significantly more externally focused than healthy respondents. The authors suggest that because the patient with diabetes or cystic fibrosis can exert some control over his illness and symptoms through manipulation of diet and self-administration of medication, he may have a greater sense of internal control. They attribute the nonsignificant difference on anxiety measures between all groups to the way the chronically ill child learns to develop coping mechanisms over time, this notion further supported by the finding that anxiety was negatively correlated with time since diagnosis.

Zeltzer et al. (1980) compared groups of chronically ill adolescents (including a cystic fibrosis group) with normal adolescents on the perceived impact of illness on their life. Interestingly, the so-called "healthy" control group reported a 30% rate of current illness (although this represented minor physical complaints) and did not significantly differ from the disease group on extent of illness reported, even though the illness groups included adolescents with serious, life-threatening diseases. In fact, with the exception of the rheumatology group, a group composed of persons in chronic pain, there were individuals in every illness group who reported "no illness." Healthy adolescents reported that illness disrupted their popularity and peer activities, whereas ill adolescents reported treatment related disruptions. Both healthy and ill adolescents had positive

future outlooks. Those reporting a positive outlook for the future included a number of adolescents who died within two weeks to six months following their participation in the study.

Summary

As mentioned above, it is difficult to draw a consistent conclusion from the reported studies. Often studies reporting serious disturbance as a consequence of cystic fibrosis were descriptive or uncontrolled. In general, it can be said that when compared with a normative population, children and adolescents with cystic fibrosis do not fare as poorly as might be suggested from results in studies where they are viewed in isolation. Research on children with cystic fibrosis, in particular, adolescents, has begun to shift from the confirmation of psychological disturbance to the ways in which the adolescent might adapt to his illness over time. This shift to an exploration of long-term individual (and family) adaptation reflects the increasing life span of individuals with cystic fibrosis (and many other serious pediatric illnesses as well). The next section will explore this idea in more detail.

Coping and Defense

Introduction

The importance of studying adaptation to illness derives from the widely recognized notion that emotional responses to the stress of chronic illness on the part of the child and his family may contribute to the course and eventual outcome of the illness. It has been

suggested that emotional responses to the disability or disease may mediate between the disease and its effects. Furthermore, while much attention has been paid to the reactive and defensive aspects of adaptation to stress, researchers are beginning to investigate the synthetic and coping aspects of adaptation (Mattsson, 1972; Coelho, Hamburg and Adams, 1974). Haan (1977), offering a framework from which to explore these issues, presents a theoretical model of ego functioning that addresses both coping and defensive modes.

Model of Ego Functioning

Haan (1977) views the ego as a combination of processes, "the ceaseless acts of people assimilating new information about themselves and their environments and accomodating to these assimilations by constructing actions that attain and re-attain an unremitting sense of dynamic equilibrium" (p. 43). The individual's everyday behavior reflects an underlying enterprise of maintaining self-consistency and making sense of himself. The three general modes of coping, defense and fragmentation (fragmentation representing a third mode that this study will not use) represent a pragmatic hierarchy of action through which the individual seeks to maintain this self-consistency: "The person will cope if he can, defend if he must,fragment if he is forced to" (p.42). According to Haan, coping and defensive modes represent variations on a continuum rather than behavioral opposites. They are assumed to share the same generic processes, differing only on a set of specified properties which are described in Table 1.

TABLE 1

Properties Of Ego Processes

Coping Processes	Defense Processes
1. Appears to involve choice and is therefore flexible, purposive behavior.	1. Turns away from choice and is therefore rigid and channeled.
2. Is pulled toward the future and takes account of the needs of the present.	2. Is pushed from the past.
3. Oriented to the reality requirements of present situation.	3. Distorts aspects of present requirements.
4. Involves differentiated process thinking that integrates conscious and pre-conscious elements.	4. Involves undifferentiated thinking and includes elements that do not seem part of the situation.
5. Operates with the organism's necessity of "metering" the experiencing of disturbing affects.	5. Operates with assumption that it is possible to magically move disturbed feelings.
6. Allows various forms of affective satisfaction in open, ordered and tempered way.	6. Allows gratification by subterfuge.

(Haan, 1977, p. 36)

Within this model, coping reflects conscious, flexible and purposive behavior, while defenses reflect rigid, channelled distortions of intersubjective reality: "In effect, coping processes continue an open system, defenses produce particular closures of the system." (Haan, 1977, p. 34)

Haan has grouped the ten generic processes into cognitive functions, reflexive-intraceptive functions, attention-focusing functions, and affective-impulse regulations. As an example of how the generic process finds expression both as a coping process and a defensive process, one can examine the ego process of sensitivity. As a coping process, it is expressed as empathy, as a defense, projection, and in its fragmented mode, as delusional. The taxonomy of the ten ego processes can be found in Table 2.

Empirical Studies on the Ego Model

Haan (1974) has used this model empirically to explore patterns of functioning associated with chronic illness and adolescence. She studied a group from the longitudinal sample at the Berkeley Institute of Human Development at adolescence and again at age 37 in order to see what patterns of adolescent coping and defending were associated with adult adjustment. Based on life assessment interviews and Q-sort measures, subjects were divided into "ego groups": 1) copers 2) defenders 3) high ego (strongly coping and defending) and 4) low ego (neither predominantly coping or defending) groups. Haan found that for the coping adults, adolescence had been an opportunity for change and also a time of conflict and disequilibrium. The defenders

TABLE 2

Taxonomy of Ego Processes

Generic processes	Modes	
	Coping	Defense
	Cognitive functions	
1. Discrimination	Objectivity	Isolation
2. Detachment	Intellectuality	Intellectualizing
3. Means-end symbolization	Logical analysis	Rationalization
	Reflexive-intraceptive functions	
4. Delayed response	Tolerance of ambiguity	Doubt
5. Sensitivity	Empathy	Projection
6. Time Reversion	Regression-ego	Regression
	Attention-focusing functions	
7. Selective awareness	Concentration	Denial
	Affective-impulse-regulations	
8. Diversion	Sublimation	Displacement
9. Transformation	Substitution	Reactions formation
10. Restraint	Suppression	Repression

(Haan, 1977, p. 35)

and low ego group (the low group using blanket denial and repressive processes) exhibited the least change between adolescence and adulthood. The high ego group did not undergo major reorganization but increased their social interaction and self-control.

This study suggests than an "open system" at adolescence, sometimes experienced as conflict or distress, led to later coping at adulthood: "It seems plausible to suggest the copers may have used this conflict in a productive way to restructure their environment." By definition, movement between developmental stages (i.e. from childhood to adolescence) is characterized by an increase in stress and an increase in demand for coping and adaptation. In Piagetian terms, the stage-transitional child is disequilibrated. In Haan's terms, it is a time when intrasubjective and intersubjective equations are imbalanced. Erikson (1959) describes the dialectic of adolescence where it is necessary to both preserve continuity and integrate change. (This is akin to the notion of autonomy and relatedness discussed earlier). According to Haan (1977), if the individual has to protect or defend himself against this imbalance (of adolescence, for instance) and also protects and defends against the new opportunities presented by this transition, he may not successfully negotiate this transition. Erikson's (1968) concept of premature foreclosure as a means of resolving the adolescent identity crisis is an example of a compromised solution.

In a second study, Haan (1977) explored the patterns of ego processes associated with chronic illness. She studied a group of

adult males and females, collecting records on their histories of hospitalizations and illnesses from birth to age 35. She found that men's difficulties were more closely related to their ego processing than women, suggesting that illness is of more social-psychological concern for males. At age 37, chronically ill males were more empathic and expressed their feelings by both coping sublimation and defensive displacement. Their concentration was poor, and unlike the women who were more prone towards regression, they angrily externalized their difficulties.

Adaptation to Illness: An Empirical View

Haan's study of adolescent correlates of adult coping might suggest that in general, an open system during adolescence produces the most coping adult. However, adolescents with illness are a part of a more complicated "system." Mattsson (1972) describes the adaptational techniques which he believes help children master psychological threats and function effectively:

> The expression of anxious, sad, impatient and angry feelings at times of exacerbations, and of confidence and guarded optimism during periods of clinical quiescence is characteristic of well-adapted children with a chronic illness. In terms of psychological defenses, most of the patients use denial as well as isolation in coping with their emotional distress... they also show an adaptive use of denial of the uncertain future which enables them to maintain hope for recovery at times of crisis...(p. 306)

Unlike Mattsson, Friedman et al. (1963) make the distinction between hope and denial: "Unlike massive denial, hope does not appear to interfere with effective behavior and is entirely compatible with an intellectual acceptance of reality." This difference between Mattsson and Friedman raises an important issue: under some circumstances, can the defense of denial be the best "coping" mechanism?

Lazarus (1973) suggests that denial may be useful at the outset of stress since it allows the person time to mobilize himself. Basing their conclusion on the empirical evidence that denial is negatively related to physiological measures of arousal, Goldstein and Adams (1967), Cohen and Lazarus (1973), Houston (1971), Steiner (1970) and Katz et al. (1970) report from empirical studies that denying stress is often better than confronting it.

Katz et al. (1970) studied women with breast tumors and found that deniers experienced the least affective distress and disruption of functioning. Also significant, however, was that these deniers had waited the longest to get help after noticing the tumor.

A Proposed Model of Coping

Taking a position that differs from that of Goldstein and Adams, Houston and others mentioned above, Haan (1977) believes that denial is not a necessary consequence of stress: "The negation of information is not necessarily the empirical response to stress":

> Whenever defenses or fragmentary processes are used to negate situations, the person's possibilities are diminished in some way, for instance his opportunity to die well, with dignity and grace...Some people will find some situations so fraught with their own particular brand of terror that they will opt sooner or later for maintaining their intrasubjective coherence at the expense of intersubjective reality. In these instances, they also reachieve a balance, a false equilibration, that rests on the negation of various elements of objective and subjective reality. They choose to compartmentalize rather than to disintegrate...his defensiveness - no matter how badly he needs it - can only deprive him of the information necessary to work through the situation (p. 170-1).

Haan specifies how a person can use coping processes in the face of a life-threatening illness. She takes each generic ego process in her model and illustrates how a coping strategy can be applied to the case of serious illness: objectivity - "a recognition of the reality

of the illness or the approach of death"; intellectuality - "informing one's self of the nature of the illness and its probable course"; logical analysis - "deducing the probable effects that the illness will have personally upon one's physical capabilities or one's worldly affairs"; tolerance of ambiguity - "withstanding and coming to terms with the uncertainties that are involved"; concentration - "focusing upon one's condition, so that realistic efforts can be made to alleviate the condition or prolong one's stay"; regression in the service of the ego - "accepting the necessity of regression to allow one's self to be cared for as needed, or to prepare for the surrender which only man anticipates"; empathy - "helping relatives with their feelings and reactions"; suppression - "the incapacitation, whether temporary or permanent, is acknowledged but the concern is occasionally suppressed rather than being a matter of incessant preoccupation"; sublimation and substitution - "subliminatory and substitutive activities chosen as unique capstones and final expression of life."

CHAPTER III

STATEMENT OF PROBLEMS AND HYPOTHESES

Statement of the Problem

According to Pinkerton (1969), "In the whole of pediatrics, there is no chronic illness which merits such long-term support of parents than cystic fibrosis." Because of a continued dependence on others for care, it might be expected that the important adolescent issues of autonomy and separation will become more problematic for the adolescent and young adult with cystic fibrosis. Lefebvre (1973) suggests that what appears to be a prolonged dependence of the adolescent or young adult upon their family might reflect a postponement, or a delayed though normal course of development, rather than a replacement or absence of mature relationships of adulthood.

Since cystic fibrosis is both a chronic and fatal disease, adolescents with cystic fibrosis face a difficult paradox. During adolescence, the world begins to enlargen in both scope, opportunity and, as discussed earlier, time. But for the adolescent with cystic fibrosis, the future is instead limited and perhaps contains fewer possibilities. What might be the best pattern of ego functioning for adolescents with cystic fibrosis who are faced with the disequilibrium of adolescence as well as the chronic threat of illness and death? As discussed earlier, when the future appears both painful and unalterable, mechanisms of denial may be adaptive and reflect meaningful ways of 'coping.' Haan, however, argues that coping can entail processes that do not distort reality, in this instance, the dimensions of the disease.

The problem becomes the following: the adolescent with cystic fibrosis must prepare for a future that may or may not embrace adulthood, but the developmental tasks of adolescence and the disease of cystic fibrosis and its influence on adolescence have to be reconciled in some way. Given the nature of the disease, the adolescent with cystic fibrosis might reformulate, compress into a shorter period of time, postpone, replace or avoid the developmental tasks of adolescence. More specifically, this reconciliation may influence the way in which the future is perceived and shaped; it may lead to a different pattern of separation and attachment; or to different patterns of ego functioning. This study attempted to understand how 20 adolescents with cystic fibrosis, taking into account the very special parameters of their lives, have begun to "reconcile" their illness with particular issues of adolescence.

Hypotheses

The following hypotheses and questions were proposed:

1. Adolescents with cystic fibrosis are more defended on ego measures than a comparable group of well adolescents.

2. Adolescents with cystic fibrosis exhibit less dense and coherent future time perspectives within a shorter extension than a comparable group of well adolescents.

3. Adolescents with cystic fibrosis are more attached and less individuated than well adolescents.

4. Adolescents with cystic fibrosis who are more severely ill will exhibit a shorter and less dense future time extension and will be more defended and attached.

5. An adolescent who rates himself as his physician does on the present severity of his illness will be more coping on ego measures.

6. Adolescents with cystic fibrosis who know more about their disease are less defended and employ more coping mechanisms.

7. Adolescents who are more attached will have a shorter and less coherent future time perspective.

8. Copers will be more individuated and exhibit more extended future time perspectives.

CHAPTER IV

METHODOLOGY

Subjects

The subjects in this study consisted of 20 adolescents with cystic fibrosis, 10 males and 10 females, ranging in age from 14 to 19. Twenty adolescents without illness, 10 males and 10 females, of similar ages and backgrounds, were drawn from non-medical settings and used as a comparison group. This study originally intended to look at adolescents in their senior year of high school since it was felt that issues of separation and the future would be most salient at this time. However, since there were so few adolescents of any age with cystic fibrosis, and with a narrowing of the population towards the upper ages, it therefore wasn't possible to get a large enough group of high school seniors. Similarly, given the limited number of adolescents with cystic fibrosis, random selection wasn't possible.

Potential subjects were sought from three separate midwestern cystic fibrosis centers, each associated with a training or teaching hospital. One of these clinics, Clinic A, served a large metropolitan area, Clinic B was situated in a smaller midwestern capitol city, while Clinic C was located in a predominantly blue collar, highly industrialized city.

The exact procedure of securing subjects differed among the three clinics and was dependent upon the research guidelines and administrative structures of each particular clinic. At Clinics A and B, the adolescent and a parent of the potential adolescent subject

were informed of the study by a clinic social worker, nurse or physician when they came for a regularly scheduled clinic visit. If the adolescent and parent were both willing to learn more about the study, the investigator was then introduced as a person doing research at the clinic. After being informed about the study, if the adolescent and their parent both gave their consent, a time for administering the tests was arranged, typically during a regularly scheduled clinic visit, although if no clinic visit were imminent, a home visit was made. In addition to the test battery which took approximately 30 to 45 minutes to complete, the subject was given a questionnaire to fill out at home and return by mail to the investigator.

At Clinic C, the clinic physician initially contacted the parents of all the age-appropriate adolescents by phone. If permission was received from both parent and adolescent, they were contacted by the investigator who informed them about the study in greater detail. For those who agreed to participate, either an appointment was made during a regularly scheduled clinic visit or a home visit arranged.

Ten subjects were drawn from Clinic A, 5 subjects from Clinic B and 5 from Clinic C. Among all three clinics, potential subjects refused to participate. However, only in Clinic C where contact was initially made by the physician over the phone did parents refuse to have their child involved. Among all the clinics, the refusal rate was about 20 percent. This included parents who refused to have their child participate, refusal by the adolescent or, on two occasions, subjects who completed the test battery administered by the examiner but failed to return the questionnaires. With only two exceptions, introduction to the study by a health care team member during a

regularly scheduled visit consistently led to participation in the study. In contrast, at Clinic C, where the initial contact was made with the adolescent and his parent over the phone by the physician, the refusal rate was significantly higher. One might speculate that this latter approach placed it outside the normal workings of the clinic and health care team, thus making the study appear more formidable and foreign.

A group of 20 adolescents without illness served as a comparison group. These well adolescents, taken from non-medical settings, were matched for age and sex. Age distributions for both adolescents with cystic fibrosis and well adolescents can be found in Appendix A.

Instruments

Instruments measuring future time perspective, ego patterns of coping and defending, and the degree of attachment and individuation were used in this study. In addition, adolescents with cystic fibrosis were given a test to see how much they knew about cystic fibrosis, and they rated themselves and were rated by their physicians on their present level of health. These measures are described below.

Separation Anxiety Test

The Separation Anxiety Test is believed to elicit patterns of response typical of the way an adolescent might handle issues of separation and individuation. This test was developed by Hansburg (1980) and was designed to explore Bowlby's notion of autonomy and relatedness. In this study, it was used as a measure of how the normative issue of separation and individuation was managed by the two groups.

The Separation Anxiety Test is comprised of twelve pictures of separation scenes. Each picture is followed by a caption which describes the separation situation. Each picture is also followed by seventeen separate statements which complete the sentence, "the child feels..." These sentences are designed to reflect particular separation reactions: well-being, rejection, withdrawal, somatic reaction, grief or loneliness reaction, evasive denial, adaptation, phobic reaction, anxiety, projection, anger, identity stress, intrapunitive response, fantasy denial, sublimation, empathy and intellectual dysfunction. The subject can endorse as many items as he wants for each picture.

Hansburg grouped these reactions into patterns which he believed represented more fundamental factors. The factor of individuation includes the separation reactions of adaptation, well-being and sublimation. Attachment includes rejection, loneliness and empathy. There are five other factors (separation hostility, separation pain, reality avoidance, intellectual dysfunction-sublimation and self-love loss) but these were not specifically addressed in the present study. The attachment percentage is obtained by dividing the total number of responses in the test into the total number of rejection, empathy and loneliness reactions endorsed by the subject. An individuation percentage is obtained by dividing the total number of responses into the sum of adaptation, well-being and sublimation reactions endorsed. Copies of the twelve test pictures comprising the separation Anxiety Test can be found in Appendix B.

Future Time Perspective Measures: Introduction

Two major variables of temporal experience, time orientation and time perspective, have become dominant in the body of research concerned with personality-temporality relationships. This study was not concerned with time orientation (a variable more important in the study of psychopathology) but focused exclusively on time perspective.

Most of the research on time perspective has been centered on future time perspective, defined as "the timing and ordering of personalized future events" (Wallace, 1956; Kastenbaum, 1961). This concept has been empirically investigated, but because different methodologies and definitions of future time perspective have been employed in various studies, it is difficult to compare results and draw generalizations from the literature. (Some of the literature concerning adolescence and time perspective was explored in an earlier section).

A number of characteristics of future time perspective have been defined and employed in various studies: extension is a characteristic that measures how far ahead a person extends his thoughts; density describes how populated with events this future appears to be; and coherence measures how well organized this future is.

Kastenbaum (1961), in an attempt to validate the assumption that characteristics of future time perspective reflect an underlying unidimensional concept, tested 209 high school seniors (107 males and 102 females) on measures of extension, density, coherence, and the additional measure of directionality (defined as the extent to which a person sees himself as moving forward from the present moment to the future). He factored these temporal measures along with other

measures of personality and intelligence, and found that one major factor emerged, with three of the four temporal variables loading on this factor. Measures of extension, coherence and density were positively correlated with each other. Only the temporal variable of directionality was unrelated to the other temporal measures.

While Kastenbaum's study might have added support to establishing the validity of the unidimensional nature of future time perspective, another problem has been the many different means of measuring this concept. One dimension on which these measurements vary is the degree of structure implicit in the tasks. Story completion tasks which include temporal anchorings (i.e. which mention an hour or a time of day when the story is taking place) elicit a powerful set towards utilizing a day as the temporal unit. Kastenbaum (1961) found that while temporally-structured story roots correlated .56 with each other, and temporally-unstructured story roots correlated .64, the correlation between these two types of tasks was only .17.

There is conflicting evidence about the degree to which structured or less structured tasks are discriminating. Kastenbaum (1961) found that the structured story roots loaded more heavily on the generalized temporal factor. But in an empirical study, Wallace (1956) found that on a measure of extension, unstructured story roots differentiate normal adults from schizophrenic adults better than structured story roots. Says Lessing (1967), "the differing content demands of these two types of instruments result in their actually measuring two separate phenomena, long-range future time persepctive and short-range future time perspective." Lessing found that tasks which ask a subject to respond to specific socio-cultural milestones

will elicit more stereotyped developmental frames of reference and will be less apt to tap personal and individualized structuring of time.

Thus, some of the low intercorrelations between different measures of variables of future time perspective (such as the low correlations between the Story Completion Test and the Incomplete Sentence Test and Events Test, the latter two tests requiring the listing of ages for personal future events, Wallace, 1956; Lessing, 1967) can be attributed, in part, to the different demand characteristics of these various instruments.

Three characteristics of future time perspective were chosen for this study. Extension was defined as "the time intervening between the present and the most distant future personalized event" (Rabin, 1978) or the length of the future time span. Density is "the number of future events listed, in a free response situation, within the given temporal extension" (Rabin, 1978). Coherence refers to "the consistency of the ordering of these personalized events within the future extension period," (Rabin, 1978) or "the degree to which elements or events in the future time span are meaningfully related" (Wallace, 1956). More simply, coherence is the measure of the ability to manage the contents of the extension. These characteristics of future time perspective were measured through a number of experimental tasks which are described below.

Incomplete Sentences Test

The Lessing Incomplete Sentences Test (Lessing, 1972) was used to measure extension. This nine item test is composed of incomplete sentences. The subject completes each sentence with the age they think

is appropriate. This test is a direct measure of the extension of personal time in a free fantasy situation. The questions are not temporally anchored by particular life events and therefore do not impose strong demand characteristics on the respondent. (See Appendix C)

Sequence-Arrangement Task

The subject was first presented with the following question:

> We all think about our future. I would like you to tell me as many things that may happen to you during the rest of your life.

Each event was recorded on a separate card and its ordinal rank in the series of events noted. After each response was given, the examiner asked the subject:

> How old might you be when that happened?

The age for each event in the series was recorded on a separate sheet. At the end of the testing session after the other tasks had been administered, the examiner presented the cards on which the events given previously had been written and the following instructions were given:

> Arrange these cards in the order in which they might occur.

The sequences of events presented by the subject were recorded. If a person arranged the sequences in identical order on both occasions, he could be said to have a perfectly coherent organization of his future experiences. A deviation from correspondence between the two administrations would mean a lack of coherence. A measure of the density of the future time perspective was derived from this task. Density equalled the number of events presented by the subject. The mean score on this semi-projective test was used to measure extension.

Events Test

The Events Test was composed of statements describing common life events. (See Appendix D). The following instructions were given:

> I'm going to read you a series of events which happen to a lot of people. I want you to tell me how old you might be when the event described might happen to you.

As discussed above, because this test includes specific socio-cultural milestones, it was more apt to elicit stereotyped frames of reference in contrast to a more personal structuring of the future as found on the Incomplete Sentences Test. Some items used in previous administrations of the Events Test (Wallace, 1956, Lessing, 1972) were not used in the present administration. For example, the item, "How old might you be when you die," was not included in this administration. The mean score provided a second measure of extension derived from this more structured test.

Haan's Model of Ego Functioning

Measures of coping and defense were derived from scales based on Haan's (1977) model of ego functioning. This model and its underlying assumptions were presented in an earlier section. In brief, Haan proposed a model consisting of 10 generic processes, each having three modes of expression: coping, defense and fragmentation (although only coping and defensive processes were used in this study). The 10 generic processes are divided into four sectors: 1) cognitive functions 2) reflexive-intraceptive functions 3) attention focusing functions and 4) affective-impulse regulations. As discussed above, the model rests on the assumption that both coping and defense processes share the same generic process, differing only on a set of specified properties (See Table 1). Within this model, coping is defined as

"conscious, flexible, purposive behavior oriented to the reality requirements of the situation," while defenses reflect "rigid, channelled distortions of intersubjective reality and logic," allowing "covert impulses without directly addressing the problem."

A series of 20 individual and 6 summary functions were adapted to the California Personality Inventory on the basis of judges's ratings of 243 adult subjects. Cross-validities and test-retest reliabilities and correlations with previously established scales were, on the whole, acceptable. (Normative data is available for both student and adult subjects. See Appendix E). These CPI based ego scales resulted in a median validity coefficient of .36 for men and .38 for women. (Validity coefficients for all the scales can be found in Appendix E). Because there was a great deal of redundancy between the scales (with four or five stable configurations consistently emerging), the coping and defense rating scales were factor analyzed and scales created from these resulting factors. (The factor loadings for men and women can be found in Appendix E.)

The first factor for males had positive loadings on the coping processes of objectivity, intellectuality and substitution, and negative loadings on the defenses of displacement, regression and projection. The first female factor is similar, although it doesn't include the defense factors. Haan (1977) has called this factor, Controlled Coping, since it describes a constellation of ego processes suggesting a personality that is cognitively capable and well-socialized.

The second male factor consists of negative loadings on the defenses of repression and reaction formation, and positive loadings on the coping processes of empathy and regression in the service of the ego.

For females, only the coping processes of empathy, suppression and regression in the service of the ego were positively loaded on this factor. No defensive processes were related. Labelled Expressive Coping, this factor "seems to reflect an emphasis on interpersonal and intrapersonal accuracy as well as a heightened flexibility and creativity." (Haan, 1977)

For men, Structured Defense is loaded most highly on the defenses of intellectualization, rationalization, projection and isolation, while for females, the highest loadings were on the defenses of regression, intellectualization and rationalization. Haan describes this factor as "a sophisticated and well-integrated pattern of self-protection."

The fourth and final factor, Primitive Defense, consisted of negative loadings for men on the coping measures of concentration and sublimation, with positive loadings on the defenses of regression and doubt. The final female factor consisted of positive loadings on the defenses of reaction formation, denial and regression (sometimes referred to as the 'hysterical triad'), with negative loadings from the coping process of tolerance of ambiguity. This factor is seen to reflect "a thin, disorganized and poorly integrated defense pattern" which contrasts with the more integrated pattern of Structured Defense (Haan, 1977). Interestingly, doubt and regression are found in the Primitive Defense factor for men, but they were also found in the Structured Defense factor for women.

While reliability coefficients are generally lower for the four factors than for many of the individual scales of coping and defense, it was nonetheless decided to use these four factors, along with the

Summed Coping and Summed Defense measures (the sum of the 10 coping scales and 10 defense scales respectively) as measures of coping and defense since these measures provide a way of meaningfully reducing the large number of individual scales.

Cystic Fibrosis Questionnaire

Lefebvre (1973) described half of her adolescent and young adult subjects as having a good to excellent understanding of cystic fibrosis. The five subjects who had the most distorted view of cystic fibrosis included three subjects from families where there was a major denial of the diagnosis, and two others who had witnessed the prolonged death of another adolescent with cystic fibrosis. It has been hypothesized that coping and defensive strategies are associated with the degree of knowledge or understanding psychologically permitted by the individual. A multiple choice test covering the etiology, genetics and treatment of cystic fibrosis was created by this researcher. This test was constructed to include the kind of information most typically encountered in the regular routines of adolescents with cystic fibrosis. This sixteen item true-false test can be found in Appendix F.

Physician and Patient Ratings

The Shwachman Scale (see Appendix G) is the most commonly used instrument to assess the health of an individual with cystic fibrosis. A health care provider well acquainted with the adolescent, either a nurse or physician, completed the scale based on the most recent assessment of that youngster's health. (This information was not shared with the adolescent.) This numerical assessment constituted

the rating of Severity of Illness. For statistical purposes, this scale was reduced to a five-point scale. A five-point rating scale which asked the adolescent to make his own assessment of his present state of health was administered at the end of the testing session. A measure of difference between the five-point physician rating and the five-point self-rating scale was derived.

CHAPTER V

RESULTS

Hypothesis 1: Adolescents With Cystic Fibrosis Are More Defended And Less Coping On Ego Measures Than A Comparable Group Of Well Adolescents.

The results suggest that adolescents with cystic fibrosis rely more on defensive ego processes than the comparable group of well adolescents. The concomitant hypothesis, however, was not substantiated. Well adolescents were not significantly more coping than the adolescents with cystic fibrosis (although the results showed the scores of the well adolescents to be consistently higher on all the coping measures.)

Defensive Processes. On the overall measure of defensiveness, Summed Defense, there was a significant difference in the predicted direction with adolescents with cystic fibrosis more defended than the well adolescents ($F=4.809$, $sig=.035$). This finding was true for both males and females in each group. There was also a significant difference in the predicted direction on the factor of Primitive Defense ($F=6.897$, $sig=.013$). But while the means on the factor of Structured Defense were in the predicted direction, adolescents with cystic fibrosis more defended, this measure approached but did not reach statistical significance ($F=2.969$, $sig=.093$). These findings suggest that adolescents with cystic fibrosis are more defended or rely more heavily on defensive ego processes than do well adolescents.

Coping Processes. On the measures of coping, the results were not statistically significant, although the means for all measures were in the predicted directions, with well male and female adolescents scoring higher on the coping measures than the adolescents with cystic fibrosis (Summed Coping, F=1.979, sig=.168; Controlled Coping, F=2.01, sig=.165; and Expressive Coping, F=.778, sig=.384). (See both Table 3 and Figure 1)

Thus, the hypothesis is partially supported. Adolescents with cystic fibrosis rely more heavily on defense processes than their well counterparts. The significant finding on Primitive Defense suggests that these adolescents rely more on what are thought to be poorly integrated patterns of defense. For males, this factor includes doubt, indicating a person's inability to commit himself to a personal course of action, and regression, where the individual expects to be cared for, acts in age-inappropriate ways and views the sources of responsibility to lie outside himself. (This factor also includes negative loadings on sublimation and concentration.) Unlike the males, where activity is thwarted through doubt and regression, for females, the factor includes repression, reaction-formation and denial (with a negative loading on tolerance of ambiguity). This constellation of functions suggests that unpleasant, threatening or problematic aspects of situations are ignored, forgotten, inhibited or altered and attention refocused on more pleasant aspects of the situation. It suggests further an inability to tolerate ambiguity and uncertainty.

The Structured Defense factor, which less clearly differentiates between the well adolescents and the adolescents with cystic fibrosis,

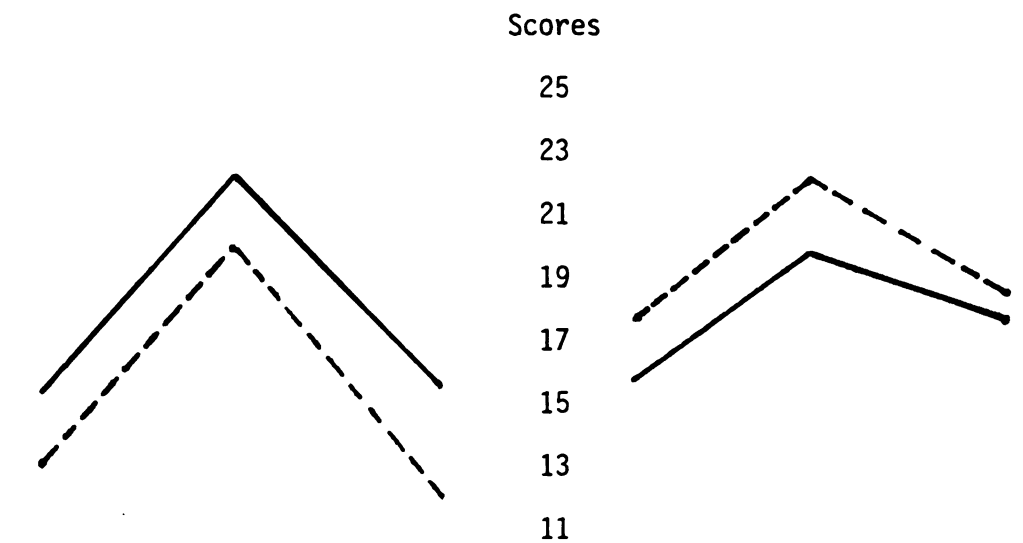
TABLE 3: Differences Between Adolescents With and Without Cystic Fibrosis on Ego Measures

	With Cystic Fibrosis		Without Cystic Fibrosis			
	Means	SD	Means	SD	F	Sig.
Ego Measures						
Summed Coping	16.10	2.29	17.30	3.14	1.979	.168
Controlled Coping	19.30	4.78	21.65	5.67	2.010	.165
Expressive Coping	17.80	2.65	18.75	4.24	.778	.384
Summed Defense	15.50	3.98	13.20	2.74	4.809	.035
Structured Defense	22.10	3.40	19.60	5.62	2.969	.093
Primitive Defense	15.25	3.37	11.80	4.67	6.897	.013

Figure 1

Patterns of Mean Scores on Defense and Coping Measures

For Adolescents With and Without Cystic Fibrosis



--- = Well Adolescents

___ = Adolescents with Cystic Fibrosis

includes a number of cognitive defensive processes, isolation, intellectualization and rationalization, and the intraceptive function of projection. For females, regression is included in this defensive constellation. The cognitive defenses might be viewed as higher order defenses, or defenses which do not distort reality or represent as great a retreat from reality as do the defensive processes in the Primitive Defense factor.

Hypothesis 2: Adolescents With Cystic Fibrosis Exhibit Less Dense And Coherent Future Time Perspectives Within A Shorter Extention Than A Comparable Group Of Well Adolescents.

This hypothesis looked at differences between well adolescents and adolescents with cystic fibrosis on four measures of future time perspective, coherence, density and two measures of future time extension. However, there were significant results only on the measures of future time extension.

Density. There were no significant differences on the measure of density between well adolescents and adolescents with cystic fibrosis, although means were in the predicted direction, well males and females having futures that were described as more dense than adolescents with cystic fibrosis (F=1.377, sig=.248). These results can be found in Table 4.

Coherence. With the exception of one case where there was a deviance of 1, all adolescents in both the comparison and experimental groups presented perfectly coherent future time perspectives. That is, there were no differences in how events were ordered when first described by the adolescent and when reordered at the end of

TABLE 4: Differences Between Adolescents With and Without Cystic Fibrosis on Measures of Future Time Perspective

	With Cystic Fibrosis		Without Cystic Fibrosis			
	Means	SD	Means	SD	F	Sig.
Density	5.30	8.30	4.90	8.30	1.377	.248
Extension:						
Incomplete Sentences	30.54	3.99	34.69	3.68	12.351	.001
Events Test	24.70	4.73	28.34	5.07	5.831	.021

testing. Therefore, as a quantitative measure, coherence does not seem to discriminate between these groups. However, a qualitative examination of the responses suggests that in describing future events in their lives, adolescents with cystic fibrosis more often than their counterparts in the comparison group used language that was tentative ("try to go to college"), had unrealistic goals ("become a pro basket ball player; probably be rich") or fantasy-laden ideas ("live out in space"). With the exception of one girl who felt the world would end in the year 2000, there were no responses among the well adolescents that could be characterized as unusual, unrealistic or fantasy-like.

Extension. On the Incomplete Sentences Test, there was a significant difference between the means for the well adolescents and the adolescents with cystic fibrosis in the predicted direction. Adolescents with cystic fibrosis had more constricted future time extensions compared with their well counterparts (F=12.351, sig.=001). This was true for both males and females. On the Events Test, there was again a significant difference in the predicted direction for both males and females (F=5.831, sig=.021), although the relationship was not as strong as on the Incomplete Sentences Test. These results can be found in Table 4.

In addition to the significant differences between mean sources on both the Incomplete Sentences Test and the Events Test, there were interesting differences on many of the specific test questions. Responding to a question from the Incomplete Sentences Test, the 'average' adolescent with cystic fibrosis feels that "being 34 is so far away that /he/ hasn't thought much about what /he/ will do then."

For well adolescents, being 44 years old is very far away. On the Events Test, the average adolescent with cystic fibrosis believes he will have reached middle age at 34, the well adolescent at 37. Adolescents with cystic fibrosis feel they are too old to be physically active at age 53, the average well adolescent at age 61. The adolescents with cystic fibrosis feel they will have "most of the things /they/ want out of life"at age 32, the well adolescents think they will have to wait until they are 43. Interestingly, on this latter question, while the differences in age are not dramatic, the differences in the frequency and range of responses are. Within a range of 25 to 65 years, 65% of the well adolescents feel that most of the things they want in life will come after the age of 30. In contrast, with a range of responses from age 14 to 80, 80% of the adolescents with cystic fibrosis feel they will have most of what they want before the age of 30. Thus, there seem to be important differences between the groups in the ways in which they respond to specific developmental milestones, as well as quantitative differences leading to either more constricted or expansive future time extensions.

Hypothesis 3: Adolescents With Cystic Fibrosis Are More Attached And Less Individuated Than Well Adolescents.

This hypothesis suggests that perhaps because of the extended and involved care that the adolescent with cystic fibrosis receives from his parents, and perhaps because of his tenuous future, adolescents with cystic fibrosis will not demonstrate the "elastic band" between attachment and self-reliance or independence described by Bowlby (1973). However, the results contradict this hypothesis and

and in fact, adolescents with cystic fibrosis are no more attached and no less individuated than their well counterparts. (See Table 5 and Figure 2)

(The attachment and individuation scores are percentage scores. For example, the attachment score consists of the total number of attachment responses endorsed by the subject divided by the total number of responses endorsed on the entire test. Thus, both attachment and individuation measures represent ratios which control for the total number of responses given by the subject since he is free to endorse as many responses as he chooses.)

Neither the Attachment nor Individuation percentages discriminate between well adolescents and adolescents with cystic fibrosis (Attachment, F=.231, sig=.634 and Individuation, F=.879, sig=.355). The data also does not conform to the norms provided by Hansburg. According to these norms, the expected Attachment Percentage should fall in the range of about 20 to 25 percent of the total number of responses. When the percentage of attachment responses rises above 25 percent, a strong need for closeness is indicated. A score below 20 percent is pathognomic of poor relatedness and suggests a failure in establishing closeness. In this study, the Attachment percentages for both the well adolescents and the adolescents with cystic fibrosis fall below the adequately attached range, scoring in the range of weak attachment. The mean Attachment percentage score for well adolescents is 19.10 (S.D.=5.38) and for the adolescents with cystic fibrosis, the mean is 18.15 (S.D.=6.86).

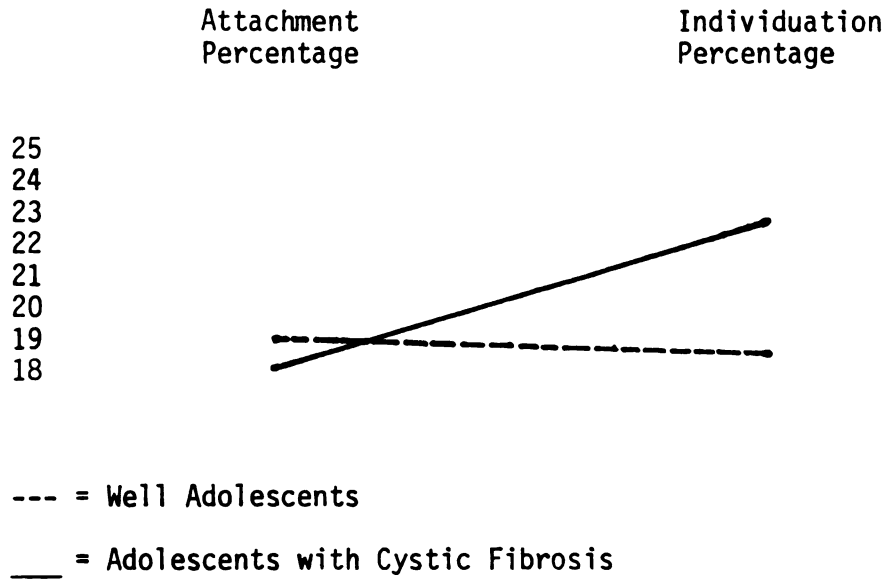
On the Individuation percentage score, according to Hansburg's normative data, the adequate range encompasses 16 to 28 percent of

TABLE 5: Means Scores on Attachment and Individuation Percentages for Adolescents With and Without Cystic Fibrosis

	With Cystic Fibrosis		Without Cystic Fibrosis			
	Mean	SD	Mean	SD	F	Sig.
Attachment Percentage	18.15	6.86	19.10	5.38	.231	.634
Individuation Percentage	22.45	15.35	18.55	10.01	.879	.355

Figure 2

Patterns of Mean Scores on Attachment and Individuation Percentages For Adolescents With and Without Cystic Fibrosis



the total responses. The Individuation percentage for well adolescents ($\overline{X}$=18.55, S.D.=10.01) and the Individuation percentage for adolescents with cystic fibrosis ($\overline{X}$=22.45, S.D.=15.35) both fall within the adequate range.

Thus, according to Hansburg's norms, both groups, well adolescents and adolescents with cystic fibrosis, are weakly attached while adequately individuated. On the analyses of variance described above, there were no significant statistical differences between the groups on either measure. These findings clearly do not support the hypothesis.

Hypothesis 4: Adolescents With Cystic Fibrosis Who Are More Severely Ill Will Exhibit A More Coherent, Less Dense And Less Extended Future Time Perspective, And They Will Be More Defended And Attached.

It was hypothesized that the present severity of illness would, in effect, exacerbate the effects of the illness. That is, those who were more seriously ill would show a heightened sensitivity to the predicted relationships between cystic fibrosis and measures of attachment and individuation, future time perspective and ego processes. On almost all measures, however, this hypothesis was not substantiated.

Coherence. Again, this measure was not used quantitatively since there was only one deviation in coherence among both the well adolescents and the adolescents with cystic fibrosis.

Density. Density was unrelated to the measure of the severity of illness. In contrast to what was predicted, those adolescents rated as more seriously ill by their physicians did not perceive

their future to be less dense. This was true for both males and females (r=.04, p=.46 and r=-.02, p=.48 respectively). (The healthier the adolescent, the higher the rating. Therefore a positive relationship from the measures was predicted.) (See Table 6)

Extension. Results on the two measures of extension did not support the hypothesis. There was a trend towards a significant relationship in the predicted direction between the measure of extension from the Events Test and the severity of illness (r=.32, p=.08), but an insignificant association between the measure of extension from the Incomplete Sentences Test and severity of illness (r=-.12, p=.30).

Coping and Defending. When males and females were grouped together, the severity of illness measure was not associated with any measures of coping and defense (Summed Defense, r=.13, p=.29; Summed Coping, r=-.07,p=.36; Controlled Coping, r=-.26, p=.09; Expressive Coping, r=-.06, p=.40; Structured Defense, r=-.15, p=.26; and Primitive Defense, r=-.07, p=.38). For females, though, there was a significant negative correlation between Summed Coping and the severity of illness (r=-.63, p=.001), which is congruent with the hypothesis; that is, the more severely ill the female adolescents with cystic fibrosis were rated to be, the lower their scores on the overall measure of coping; or conversely, the healthier the adolescent, the more coping.

Attachment and Individuation. The measure of the severity of illness was not significantly related to Attachment (r=-.02, p=.46) but was negatively and significantly related to Individuation as predicted by the hypothesis (r=-.41, p=.036). This significant

TABLE 6: Correlation Coefficients Between Severity of Illness and Measures of Future Time Perspective, Ego Processes and Attachment and Individuation Percentages.

Severity of Illness Correlated With:	Adolescents with Cystic Fibrosis (N=20)	Males (N=10)	Females (N=10)
Density	-.04	.04	-.02
Extension			
Incomplete Sentences	-.12	-.39	.33
Events Test	.32	.48	-.11
Ego Processes			
Summed Coping	-.07	.27	-.63*
Expressive Coping	-.06	-.23	.07
Controlled Coping	-.26	-.46	.01
Summed Defense	.13	.28	-.24
Structured Defense	-.15	-.19	-.16
Primitive Defense	-.07	-.18	.05
Attachment Percentage	-.02	.30	-.25
Individuation Percentage	-.41*	-.54+	-.09

*Significant at $<.05$ level.

+Approaches significance at $<.10$ level.

finding results from the contributions of the male subsample where the negative correlation between the severity of illness and measure of individuation approaches significance ($r=-.54$, $p=.06$). (These variables are unrelated in the female subsample, $r=-.09$, $p=.40$).

One can conclude that male adolescents with cystic fibrosis who are more seriously ill will be less individuated but not necessarily more attached. One can't predict patterns of attachment and individuation based on the severity of illness for females.

Hypothesis 5: An Adolescent Who Rates Himself As His Physician Or Nurse Does On The Present Severity Of His Illness Will Be More Coping On Ego Measures. (The greater the divergence between how the adolescent with cystic fibrosis rates the severity of his illness from how his physician or nurse rates his health, the less coping and the more defended the adolescent will be).

This hypothesis suggests that if the adolescent does not view his health status in the same way as his health care practitioner, he is then using defensive processes to screen out or avoid threatening information. The hypothesis, therefore, predicts a positive association between defensive processes and the measure of divergence, and a negative association between coping processes and divergence. The findings only partially support this hypothesis. (See Table 7.)

Coping. In support of the hypothesis, it was found that the greater the divergence between adolescent and physician or nurse ratings, the less coping the adolescent was assessed to be. The correlation between Summed Coping and the measure of divergence was significant and negative as predicted ($r=-.39$, $p=.05$), although this

TABLE 7: Correlation Coefficients Between Divergence Scores (Adolescent vs. Health Care Practitioner Ratings) and Ego Processes

	Adolescents with Cystic Fibrosis (N=20)	Males (N=10)	Females (N=10)
Diverence Correlated With:			
Ego Processes			
Summed Coping	-.39*	-.17	-.36
Expressive Coping	-.32+	-.63*	-.24
Controlled Coping	-.26	-.38	-.52+
Summed Defense	-.23	.32	-.64*
Structured Defense	-.04	.39	-.34
Primitive Defense	.06	-.11	.18

*Significant at $<$ .05 level.

+Approaches significance at $<$ .10 level.

association was not a strong one. The factor of Expressive Coping approached significance in the predicted direction (r=-.32, p=.09) due to the contribution by the male subsample which had a significant association between divergence and Expressive Coping (r=-.63, p=.032). Although correlated with divergence in the predicted direction, Controlled Coping was statistically insignificant (r=-.26, p=.14). (For females, however, there was a trend towards a significant association between Controlled Coping and the measure of divergence, (r=-.52, p=.07).

Defense. There were no significant relationships between the measure of divergence and any of the defense measures (Structured Defense, r=-.04, p=.42; Primitive Defense, r=.06, p=.40 and Summed Defense, r=-.23, p=.18). However, there was a difference in how males and females scored on the correlation between Summed Defense and divergence: for males, although statistically insignificant, the correlation was in the predicted direction (r=.32, p=.20); for females, the correlation was statistically significant but in the opposite direction from what was predicted by the hypothesis (r=-.64, p=.03). These directional differences between males and females were also found on the measure of Structured Defense, although the findings were not statistically significant: males scored in the predicted direction (r=.39, p=.15) while females scored in contradiction to the hypothesis (r=-.34, p=.18). The hypothesis suggested that the greater the divergence in health ratings, the greater the use of defensive processes since the adolescent is not realistically and openly acknowledging the extent of his illness. However, the findings with regard to this hypothesis are equivocal.

Hypothesis 6: Adolescents With Cystic Fibrosis Who Know More About Their Disease Are Less Defended And Employ More Coping Mechanisms.

It was expected that those adolescents who do not incorporate commonplace information about the disease of cystic fibrosis rely to a greater extent on defensive ego processes where reality is distorted or denied. This hypothesis was only partially corroborated. For males and females together, the extent of knowledge was unrelated to any of the measures of defense (Summed Defense, r=.02, p=.47, Structured Defense, r=.03, p=.46 and Primitive Defense, r=-.01, p=.48). While the correlations with the coping measures all fell in the predicted direction, extent of knowledge was significantly and weakly related to Controlled Coping only (Summed Coping, r=.21, p=.18, Expressive Coping, r=.19, p=.20 and Controlled Coping, r=.38, p=.05). (See Table 8)

Looking separately at the males and females, there were no significant correlations between the extent of knowledge and any of the ego processes, coping or defense, for the female subsample. However, for the male subsample, there was a significant positive correlation between Controlled Coping and the extent of knowledge (r=.62, p=.03) and a significant negative correlation between Summed Defense and knowledge (r=-.61, p=.032). These two correlations are consistent with the hypothesis. The male factor of Controlled Coping includes the cognitive processes of objectivity and intellectuality and the attention-focusing process of substitution (with negative loadings on displacement, regression and projection). According to Haan, objectivity refers to the ability to evaluate the dimensions of a situation clearly and to distinguish between one's own feelings and the facts of the situation, and

TABLE 8: Correlation Coefficients Between Extent of Knowledge About Cystic Fibrosis and Ego Processes

	Adolescents with Cystic Fibrosis (N=20)	Males (N=10)	Females (N=10)
Extent of Knowledge about Cystic Fibrosis Correlated With:			
Ego Processes			
Summed Coping	.21	-.07	-.27
Expressive Coping	.19	.25	-.05
Controlled Coping	.38*	.62*	.10
Summed Defense	.02	-.61*	.27
Structured Defense	.03	-.26	.10
Primitive Defense	-.01	-.27	.12

*Significant at $<.05$ level.

intellectuality involves the attempt to consider all possibilities and understand the truth, "even if it is against one's self interest." The process of learning about and incorporating complex and potentially painful information about a disease seems intimately related to these two ego processes and perhaps explains the significant association between the Controlled Coping factor and the extent of knowledge about cystic fibrosis in the male subsample.

It should be added that the frequency distribution of responses on the Cystic Fibrosis Questionnaire was highly skewed. Of the fifteen questions asked on the test, most subjects made only a few errors, and the mean for the questionnaire was 13.25 (S.D.=1.74). In an attempt to devise a brief questionnaire that would include commonly encountered information about cystic fibrosis, it may be that the questionnaire erred in being too simple, with too little variance for the population being studied.

Hypothesis 7: Adolescents Who Are More Attached Will Have A Shorter, Less Dense And Coherent Future Time Perspective. (The concomitant hypothesis is also true: those adolescents who are more individuated will have longer, more dense and coherent future time perspectives).

This hypothesis directly explores some of the theoretical assumptions underlying this study. It examines whether the seemingly separate adolescent tasks described earlier are related in predictable ways.

Coherence. As discussed above, coherence could not be used as a quantitative measure.

Density. Density was not significantly correlated with Attachment (r=.07, p=.34), but it was significantly correlated with Individuation (r=.36, p=.01). This finding is consistent with the hypothesis. See Table 9.

Although this hypothesis looks at the relationships between these variables among the entire sample (n=40), one can also look at possible differences between the subsamples (adolescents with and without cystic fibrosis, males and females). Males with cystic fibrosis show a significant negative correlation between Density and Attachment (r=-.55, p=.05), and a trend towards a significant positive relationship between Density and Individuation (r=.45, p=.10). (Because the above hypothesis does not specifically address the findings of the subsamples, these results can be found in Appendix H). Among the well male adolescents, there was a trend towards a significant, positive correlation between Density and Individuation and a trend towards a significant, negative correlation between Density and Attachment.

Extension. There were no significant associations between either measure of extension and the measures of Attachment and Individuation. However, there was a significant correlation between the Events Test extension measure and Individuation among male adolescents with cystic fibrosis (r=.75, p=.01) and a trend towards significance among the females. (See Appendix H) This finding suggests that those males with cystic fibrosis who are more individualized will also project themselves farther into the future when describing normative developmental milestones. Among the well females, there was a significant positive correlation between both measures of

TABLE 9: Correlation Coefficients Between Attachment and Individuation Percentages and Measures of Future Time Perspective. (N=40)

Attachment % Correlated With:	
Density	.07
Extension:	
Incomplete Sentences	-.17
Events Test	-.20+
Individuation % Correlated With:	
Density	.36*
Extension:	
Incomplete Sentences	-.07
Events Test	.07

*Significant at $<$ .05 level.

+Approaches significance at $<$ .10 level.

extension (r=.66, p=.05) and Incomplete Sentences extension (r=.54, p=.05).

In summary, when looking at the entire sample, Density was positively correlated with Individuation as predicted, while the measures of extension were not significantly correlated with either Attachment or Individuation.

Hypothesis 8: Copers Will Be More Individuated And Exhibit A More Extended Future Time Extension. Concomitantly, defenders will be more attached and exhibit a more constricted future time extension.

As defined by Haan, defensive ego processes are thought to reflect an overall constriction in how the world is experienced and a retreat from an examination of reality and the future. In contrast, coping processes include behaviors that are purposeful, flexible and "pulled towards the future" while oriented to the present reality. One might theoretically predict, then, that ego processes are related to how an individual shapes his future and manages the tasks of individuation and separation. A number of specific relationships among the variables are predicted: 1) attachment was expected to be negatively associated with the measures of coping and positively associated with the defense measures 2) individuation was expected to be positively associated with the measures of coping and negatively associated with the defense measures and 3) extension was expected to be positively associated with individuation and negatively associated with separation.

Attachment and Individuation. All the coping measures were significantly and negatively correlated with Attachment as predicted.

(Summed Coping, r=-.26, p=.05), Controlled Coping, r=-.48, p=.001 and Expressive Coping, r=-.30, p=.029). That is, those adolescents who were more attached were less coping. However, coping factors were not significantly related to the measure of Individuation. (See Table 10) And, the defense measures were not significantly associated with either Attachment or Individuation.

Extension. The measure of Primitive Defense was negatively and significantly associated with both measures of extension as predicted (Events Test extension, r=-.28, p=.039 and Incomplete Sentences Test extension, r=-.32, p=.02). Controlled Coping was positively and significantly associated with the extension measure from the Incomplete Sentences Test (r=.31, p=.027) and the Events Test extension measure (r=.37, p=.01). Summed Coping was positively associated with the Events Test extension measure (r=.34, p=.02).

As in the previous hypothesis, although this hypothesis looks at the relationships between these variables among the entire sample, one can nonetheless look at whether these relationships are different among the subsamples. One finds that males with cystic fibrosis showed significant negative correlations between Attachment and all measures of coping (Summed Coping, r=-.55, p=.05, Controlled Coping, r=-.66, p=.02 and Expressive Coping, r=-.86, p=.001). Correlations for all the subsamples can be found in Appendices I and J.

When looking at the summary of findings in Table 10, one observes that the correlations between coping and defense measures and Attachment and Individuation all fall in the predicted directions, but only the coping variables were significantly correlated. Furthermore, with the exception of Structured Defense, all the coping and

TABLE 10: Correlation Coefficients Between Future Time Extension, Individuation and Attachment Percentages and Ego Processes. (N=40)

	Attachment %	Individuation %	Incomplete Sentences Test Extension	Events Test Extension
Summed Coping	-.26*	.14	.19	.34*
Controlled Coping	-.48*	.03	.31*	.37*
Expressive Coping	-.30*	.07	.10	.08
Summed Defense	.02	-.11	-.17	-.12
Structured Defense	.15	-.07	.23+	.01
Primitive Defense	.16	-.19	-.32*	-.28+

*Significant at $<.05$ level.

+Approaches significance at $<.10$ level.

defense measures were correlated in the predicted direction with both measures of extension, although again, only some of these correlations approached or attained significance.

CHAPTER VI

DISCUSSION

Introduction

This study was both a descriptive and an experimental study. It was experimental in that it compared two groups, one with and one without illness, on a number of dimensions and hypothesized specific differences between the two groups. The study was descriptive, even given its experimental design, because so little is known about this area of research. Any research in this area only begins to carve out a small part of the territory to be explored.

In essence, this study, which explored a number of variables relevant to the area of illness and adolescence, was a compilation of three studies: first, it looked at differences between two groups (adolescents with illness and adolescents without illness) on a number of variables; second, it looked at a number of variables within the illness group; third, it examined the behavior of particular variables across the two groups. The breadth of the present study was both a strength and a weakness. Because of such a broad exploration, it wasn't possible to examine each set of variables in as much depth as might have been warranted. And, this research raises as many questions as it answers. Nonetheless, it does point the way for subsequent research efforts. After reviewing the results of this research as well as discussing its methodological shortcomings, this section will discuss possibilities for future research, as well as implications for health care providers.

Methodological Shortcomings

This section will explore the methodological shortcomings that may have hindered the success of this study. These shortcomings can be grouped into two categories: subject characteristics and instrument characteristics.

Subject Characteristics. As mentioned earlier, there were a number of factors that interfered with a random selection of subjects. Adolescents with cystic fibrosis are, by definition, a rare group, but fortunately because of continual improvements in medical care they are increasing in numbers with each year. (This increase is one of the reasons for the present study.)

A second factor associated with this special sample which also limits selection has to do with the occasional concerns and reservations of a referring health care practitioner, a parent or the adolescent himself about participating in a study of this kind. Oftentimes, the health care practitioner will screen out that adolescent who already seems hesitant about speaking of his illness. Parents may be concerned that a study of this nature will bring up issues they feel shouldn't be discussed, and which aren't discussed at home. Given that some degree of acceptance has to have already occurred if a parent, practitioner or adolescent consents to participate, one has a likely confounding of the very variables one wants to study. Parents who are open, flexible and tolerant enough to allow their child's participation often have children with similar characteristics. Adolescents who choose to participate might from the outset be seen to be more coping and less defended. Health care practitioners who place particular patients on a list for possible

participation in a study are making a selection based on certain characteristics. In the present study, only one or two possible participants were considered inappropriate for the study by their health care practitioners, although doubts were expressed about the receptivity of other possible participants and these doubts were often confirmed. This mostly voluntary selection process, then, raises the real possibility that one begins the study with a more coping group which, as hypothesized, may also influence the outcome on other related variables. Though the process of consent introduces bias into the subject group, there was no way to redress this particular shortcoming.

A third factor has to do with the age of the subjects. As discussed above, while the original intention of this research was to study adolescents who were in their senior year of high school, it was impossible to acquire a large enough sample with such strict age criteria. Therefore, the criteria were broadened to include both older and younger adolescents. Adolescence is not a uniform period, a fourteen year old is surely strikingly different than a nineteen year old. And while less is known about how age influences coping and defense measures, it is known that at least through adolescence, age is linearly associated with the measure of future time extension. Therefore, age serves as a possible confounding factor, making it more difficult to clearly interpret the results.

Finally, the small sample sizes stretched the limits of the statistical procedures. It may be that given larger sample sizes, trends toward significance may have emerged as significant findings.

Instrument Characteristics. There were many methodological shortcomings with a number of the instruments used in this study. While most of these problems will be examined as they arise in relation to particular hypotheses, a few general remarks about the instruments can be made at the outset. Further pretesting of some instruments may have highlighted some potential problems. Further pretesting of the Sequence-Arrangement Test could have indicated a need for a greater time interval between the two administrations. While some pretesting was done on the Cystic Fibrosis Questionnaire, more testing might have pointed out its restricted range (although there were not enough adolescents with cystic fibrosis on whom to do extra pretesting).

There were some statistical shortcomings inherent in the tests themselves. One example is the ego process factors used to measure coping and defense. The original attempt behind creating the factors was to reduce the redundancy in the scales, but reducing the individual scales to factors may have resulted in an accompanying loss of validity. The ego factors generally have lower validity coefficients than the individual scales (although there are problems with validity on a number of the individual scales as well). Because of the low validity coefficients, Joffe and Naditch (1977) suggest that a number of the scales and factors be used and interpreted cautiously. (For both males and females, weak indices include the ego processes of rationalization, sublimation and substitution; for males, this also includes the factors of summed and primitive defense and expressive coping.)

The use of the factors leads to a second problem. In using the factors in place of the twenty individual measures, one can't know

what particular ego processes in the factors may most be accounting for the significant results. Nonetheless, as an introductory study to determine whether this instrument might be useful in further research, there were enough significant findings to recommend further work with these scales. One might even want to develop a group 'ego profile' that could chart the twenty individual ego processes, making specific hypotheses about the separate scales.

Summary of the Findings

Hypothesis 1. The results showed that adolescents with cystic fibrosis were more defended but not significantly less coping than well adolescents. These adolescents were more defended across all defensive modes and more often relied on "primitive" modes of defense including regression, denial, repression, doubt and reaction formation. Within Haan's model, these adolescents would be labeled as 'defenders.' Interestingly, there were no differences between well adolescents and adolescents with cystic fibrosis in the overall pattern or configuration of coping and defense processes. Instead, there were only quantitative differences between the two groups, with the greatest differences on the Primitive Defense factor.

The empirical literature suggests that parents of children with chronic illnesses, including cystic fibrosis, have been more protective, restricting their child's independence to a greater extent than parents of children without illness (McCollum and Gibson, 1970). The results suggest that these adolescents rely more on regressive modes (expecting to be taken care of and viewing the locus of control to lie outside themselves). This may reflect an acceptance of the parents' needs to protect, restrict and take care of these children. However,

when Kellerman et. al. (1980) used a specific measure of locus of control to study adolescents across varying groups of illnesses, they found that adolescents with cystic fibrosis scored comparably with well adolescents, both groups exhibiting higher internal than external control. A further look at the specific defense processes contributing to the significant finding on Primitive Defense is warranted in subsequent studies.

The significant finding on the Primitive Defense factor for adolescents with cystic fibrosis does not support a 'psychological innoculation' theory. This theory would imply that coping mechanisms are developed over time in response to continued stress. But this finding also does not indicate whether these defensive strategies are stable and well-entrenched or whether the adolescent is "disequilibrated." Kellerman et. al. found no differences on measures of state trait anxiety between adolescents with varying illnesses and well adolescents. They found, further, that anxiety was negatively correlated with the time since diagnosis, suggesting that the chronically ill child learns to develop coping mechanisms over time. (An informal validation for this latter finding comes from an experience in the present study where the one adolescent who was diagnosed in adolescence - rather than in infancy as were all the other adolescents in this study - was one of only two adolescents who did not return his questionnaire and thus could not be included in the study.) While the present study provided a descriptive picture of the relative degree to which coping and defense strategies were employed, it may have been useful to have included an additional measure of anxiety, as well as a measure of social competence. These measures might have

provided a means of telling whether the defensive pattern endorsed by the adolescents with cystic fibrosis were indeed 'protective,' ego-syntonic and well-entrenched, or whether they are still fluid and reflect a process of continuing change. They might help discern whether this seemingly 'defensive' adaptation in some way comprises a coping pattern by lowering anxiety and helping in adaptation. However, Haan (1974), in her study of patterns of adolescent coping and defending, found that 'defenders' and the low 'ego group' (a group neither predominantly coping or defending) exhibited the least change between adolescence and adulthood. This differs from the defensive "holding" pattern described by Freud (1973) where defensive processes enable the developmentally changing person to work through a time of transition. This "holding" pattern corresponds more to Haan's notion of coping which refers to "an ongoing, open organization."

Hypotheses 2. This hypothesis looked at differences between the group of well adolescents and adolescents with cystic fibrosis on measures of future time perspective. As discussed above, coherence did not discriminate among any of the adolescents. In his study of high school seniors, Kastenbaum (1961) used a three week time interval between two administrations of a sequence-arrangement task and was able to assess coherence. In the present study, the approximately 45 to 60 minutes between the first and second administrations of the sequence-arrangement task did not prove to be an adequate interval since the adolescents in both groups had no difficulty consistently ordering the events in their future. Studies using psychiatric patients found coherence to be a discriminating measure even given a short time interval between administrations. However, a longer

interval seems to be required for non-psychiatric populations. The measure of density also did not prove to be a very discriminating variable. However, results on this measure were all in the predicted direction and it may be that given a large sample, one might have had more statistically significant results. While the quantity of events described by the two groups of adolescents didn't differ significantly, there was, as noted earlier, a qualitative difference. As discussed in the previous section, while the future goals did not always differ between the two groups, the ways in which they were presented often differed strikingly. Even a look at the kind of language used highlights important differences. The adolescents with cystic fibrosis often presented their future in tentative, conditional ways: "I'd like to get married; I'd like to work: maybe when I turn 17 or 18 I'll get a job as a physical therapist." The boy who during the testing found out he had new, serious complications to his illness was most glib: "Get a job in the hospital and probably be rich." It may be that an extended or semi-structured interview would have elicited and been sensitive to these kinds of qualitative differences.

As predicted, adolescents with cystic fibrosis did show a more constricted future time extension. The majority of these adolescents felt they would have most of what they wanted before the age of 30, while the majority of well adolescents thought they would have most of what they wanted after the age of 30. No adolescent spoke directly about considering their future in light of their illness, although the family of one sixteen year old boy had recently bought a business which they hoped their son would manage when he graduated from high

school. It was planned that if he had periods when he needed to be in the hospital, other family members would share the responsibility of running the business. (This information was shared by one of his parents when he was out of the room.) On the Sequence-Arrangement Task, this adolescent gave only one response: "After graduating, I'll work for my dad." Other adolescents presented future scenarios similar to those of the well adolescents which included marriage and children, although in contrast to the well adolescents, many of whom presented elaborate plans after retirement, none of the adolescents with cystic fibrosis talked about their post-retirement activities.

A number of contradictory interpretations might be brought to bear on this finding of a constricted future time extension among the adolescents with cystic fibrosis. According to the empirical literature, maladjusted and unhappy adolescents showed more constricted future time extensions because the future is no longer available as a place to project wish-fulfilling fantasies. Are adolescents with cystic fibrosis unhappy adolescents and is this the factor that accounts for the more constricted extension? The younger the child, the farther away the future seems to be and, according to Fraisse (1963), the "temporal horizons" expand as the individual gets older. Does this constricted extension have to do with a more childlike temporal orientation where the future seems more remote and less real than for the 'older' adolescent? Or, is this a defensive posture as suggested by Wohlford (1966) who found that unpleasantness in the future is avoided? Is it a defensive posture resulting from an awareness of death as suggested by Dickstein and Blatt (1966) who found that adolescents with a high manifest concern about death had

shorter future extensions? Or, does it imply a more realistic understanding of some of the limitations imposed by cystic fibrosis on the life span? The results from the previous hypothesis may lend some help in interpreting this issue, although a number of questions will nonetheless remain unanswered and will be addressed again at the end of this section.

There is no direct evidence from this study to suggest that adolescents with cystic fibrosis will have a more childlike approach to the future. The higher defensiveness on the ego factors as described in Hypothesis 1 would tend to suggest that this constriction is a defensive posture as described by Wohlford, Dickstein and Blatt, rather than a realistic appraisal of the limitations imposed by the disease, but this interpretation is given with caution since the evidence for this interpretation is indirect.

Hypothesis 3. The measures of attachment and individuation did not act in predictable ways and did not discriminate between the two groups. It may be that this hypothesis was a poorly conceived one, or it may also be that the measures did not adequately measure what they were supposed to measure. Both of these possibilities will be explored.

As a testing instrument, the Separation Anxiety Test falls somewhere between a projective and a structured task. Unlike a projective task, the respondent endorses predetermined responses that are provided as part of the test. One assumption underlying the Separation Anxiety Test is that "children can select and report reactions to separation which genuinely reflect how they feel." (Hansburg, 1980). The Separation Anxiety Test is also thought to reveal "what

mechanisms of defense against separation anxiety are mobilized." However, since the intent of the test statements are obvious to the respondent (one clearly endorses a response that says one is frightened or angry or miserable), those who don't want to openly acknowledge these feelings might instead respond defensively. For instance, one boy with cystic fibrosis had a highly positive, dense, well-elaborated future on the Sequence Arrangement Task. Having recently received a scholarship, he was looking forward to college and a career, and he was planning to live a long life. Out of all the adolescents in the study, he had the most constricted record on the Separation Anxiety Test, endorsing only those items reflecting adaptive reactions and well-being: "He will do his best to get along; he is free to do what he wants; he was just going away to have some fun." (However, following strictly the interpretation rules devised by Hansburg, this protocol would not be interpretable because of its low number of responses). Other than the low number of responses and the lack of variety among the responses endorsed, both characteristics suggesting a highly constricted profile, the response pattern suggests a well-adapted though overly individuated adolescent. One might infer, though, that the constant and insistent presentation of himself in the interview as cheerful and able reflects a somewhat brittle and inflexible adaptation given the constriction and inflexibility of his response patterns on the test. This example was used in order to illustrate that one can make use of the Separation Anxiety Test if one takes more than the quantitative measures into account. Including all nine factors instead of only the individuation and attachment factors might also have added other information that could have led

to differences between the two groups . The transparency of the responses perhaps interferes with a more sensitive, quantitative measure since it confuses the "genuine" response with the "defense against separation anxiety" as in the example described above. This attribute of the test may have something to do with the insignificant findings on this hypothesis.

One must also take the other position: rather than an inability of the test to tap deeper, underlying responses to individuation and attachment stimuli, there are indeed no differences between well adolescents and adolescents with cystic fibrosis. One then has to ask what might have been wrong with the initial hypothesis. The literature suggests that adolescents with cystic fibrosis were likely to be more attached and less individuated. In this study, both groups were only weakly attached when compared with Hansburg's normative data. In fact, when looking only at the mean scores, adolescents with cystic fibrosis were both more individuated and less attached than their well counterparts. However, the mean scores for the well adolescents more closely approximate Bowlby's "elastic band" and Schaffer's (1968) "balance" between individuation and attachment; that is, there is only a slight difference between the individuation and attachment means for well adolescents compared with the means for adolescents with cystic fibrosis where these factors are more imbalanced.

Hypothesis 4. In her study, Farkas (1973) divided her sample into good versus poor current levels of physical functioning and found no differences between the two groups on measures of future time perspective. Similarly, in the present study, results from the correlations between the severity of illness and the measures of future time

perspective, ego processes, and attachment and individuation percentages were equivocal. It had been hypothesized that the more severe the illness, the less dense and more constricted the future time perspective and the more defended and attached the adolescent. While most of these correlations were insignificant, a number of relationships were significant: the more severe the illness, the less coping the female adolescent; the more severely ill the male adolescent, the less individuated he was. Thus, for males, the process of individuation seemed more vulnerable to being interfered with by his illness. This finding is an important one and is similar to Haan's finding where patterns of ego processes were more closely related with patterns of chronic illness among men than women. She suggested that illness has greater social-psychological consequences for men. That is, illness may more seriously interfere with the developmental task of individuation for males who are expected to be more independent while women are permitted greater degrees of dependent behavior.

The greater association between coping and severity of illness for females may have to do with an artifact of the study where females turned out to be somewhat more seriously ill than the males in the sample. Three out of the ten males in the sample were given the highest ratings, thus indicating only minimal symptomatology. In contrast, only one female received this rating and three of the ten females were in the hospital during some part of the testing process for treatment related to their illnesses.

Hypotheses 5. In was expected that adolescents who rate themselves differently from their health practitioner are not realistically acknowledging the parameters of their disease. This hypothesis

was only partially supported. Findings from another study might help in understanding why the results for this hypothesis were not more convincing. Kellerman et. al.(1980) found that when adolescents with illnesses are asked to rate themselves on a present measure of health, they do not compare themselves with the general population of well adolescents. Rather, they use themselves as a kind of baseline. For example, if they're not in the hospital and haven't had any recent difficulties, even if they have cystic fibrosis or leukemia, they nonetheless feel "relatively" healthy. Thus, a self-rating on health is a "relative" measure and when children with life-threatening illnesses feel "relatively" good, they will rate their health as 'good.' In the present study, some of the children who participated were in the hospital during a part of the testing processes. They nonetheless did not rate themselves as seriously ill, even as they sat filling out the rating sheet in a hospital bed. Thus, the physician or nurse may have been rating the adolescent in "absolute" terms according to the Shwachman scale while the adolescents with cystic fibrosis were rating themselves in relative terms. One might have circumvented this problem by asking a different question. Rather than only asking, as the present study did, "How would you rate your health today?" one could also ask, "How do you think your physician or nurse would rate your health today?"

The results on this hypothesis and the problems with interpreting the results point out the difficulties in using the factor groupings rather than the individual ego processes. It is very difficult to know beyond an inference what specific processes might be accounting for a particular correlation between a factor and another variable.

For example, when looking at the unexpected finding of a negative correlation between defense and divergence among the females with cystic fibrosis, one wants to know which of the specific defense processes might be most significantly contributing to this finding.

Hypothesis 6. When the Cystic Fibrosis Questionnaire was being designed, it seemed important to include information that might have been encountered during a standard visit to any of the clinics. By including often-encountered information one could also determine whether clinics were successful in disseminating the kinds of information they thought all adolescents should know about. With hindsight, it seems as if one would have had a stronger test of the hypothesis if there were a greater range of questions, from the commonly encountered to the highly specialized fact. In this way, one could then tap those adolescents who deal with the world by trying to learn everything they can about their illness in contrast to an adolescent who casually picks up more commonplace information in the course of a clinic examination.

Among the males with cystic fibrosis, the extent of their knowledge about cystic fibrosis was significantly and positively related to the measure of Controlled Coping and negatively related to Summed Defense. (There were no significant relationships for the females.) Since the factor of Controlled Coping includes the cognitive processes of objectivity and intellectuality (as well as the attention-focusing process of substitution) one again might want to look at the individual factors in a subsequent study to see whether the cognitive factors (which deal with how information from the world is managed) indeed account for the significant associations.

Because the findings are correlational, one can't determine which variable precedes the other: does greater information lead to greater coping and less defensiveness, or does greater defensiveness mitigate against receiving more information about the illness? The latter suggests a particular defensive style. This hypothesis has important implications for practitioners working with adolescents with cystic fibrosis. If in subsequent studies it can be determined that more information leads to a less defensive style, practitioners would want to spend more time with the adolescent patient disseminating information. Theoretically, this would lead to a greater sense of their ability to control, plan and engage in purposeful behavior. If the defensive style mitigates against taking in information, the practitioner will have to appreciate that with this particular adolescent, more work will need to be done to get the same amount of information across.

Hypotheses 7 and 8. These final two hypotheses were constructed for two purposes. First, they attempted to explore some of the theoretical assumptions underlying this study and to explore the behavior of some of the study's major variables and the relationships between them. Since coping processes are described as purposeful and "pulled towards the future," it was hypothesized that measures of future time extension would be positively related to coping measures. In the same way, since individuation implies a moving out beyond the immediate sphere of family into a realm of future persons and possibilites, it was also hypothesized that individuation would be related to coping and in turn to extension. And, while not directly addressed in the hypotheses, there was a brief examination of whether these

relationships would be different for adolescents with cystic fibrosis compared to well adolescents.

Among all the adolescents, those adolescents who were more individuated had more dense future time perspectives; adolescents who were more attached were less coping; adolescents who were more coping on the summed and controlled coping factors had longer future time extensions; and finally, those adolescents more 'primitively' defended had shorter extensions. These findings lend some support to the hypotheses. However, one gets a different perspective on these findings when examining the subsamples.

One finds that male adolescents with cystic fibrosis who are more attached have futures that are seen to be less dense, while more individuated adolescents had more extended and dense future. Among the male adolescents with cystic fibrosis and the well females, there is a relationship between individuation and longer future time extensions. Further, highly attached well females were more defended, while highly attached males with cystic fibrosis were less coping but not necessarily more defended. This latter finding is an interesting one. Among the well female adolescents, attachment is associated with organized defensive patterns, but for male adolescents with cystic fibrosis, greater attachment doesn't lead to organized defensive patterns, but it may interfere with the development of organized coping processes.

Interestingly, while the measures of attachment and individuation did not discriminate between the two groups as described in a previous hypothesis, they did prove to be significant variables within each group. The measure of attachment seems particularly important

to the males with cystic fibrosis for whom attachment is strongly related to patterns of coping and defending. For these adolescents, individuation is also strongly associated with an increased projection of themselves into the future. Again, this may be related to Haan's finding that illness seems to have a greater impact on the lives of men for whom certain possible accompaniments to illness (e.g. regression, dependency) are much less acceptable within the male role. Thus, while one group of adolescents isn't necessarily more attached or individuated than another, the degree to which he is attached or individuated (particularly for the male adolescent with cystic fibrosis) is strongly associated with future time perspective and coping and defense processes.

In summary, there seem to be some significant relationships between the ego processes, individuation and attachment percentages, and the measures of future time extension as hypothesized. Additionally, these relationships seem fairly consistent across all the groups, although particular variables are stronger among particular subgroups as described above.

Summary

In the preceding pages, each of the hypotheses was addressed, some of them producing significant findings and some with inconsistent or equivocal results. From these results, one can derive a descriptive picture of the adolescent with cystic fibrosis as compared with his well counterpart. The adolescent with cystic fibrosis is more defended, at times using more poorly integrated, primitive patterns of defense than his well counterpart; his future is not less dense or coherent but this adolescent does not project himself as far into

the future because his future time perspective is a shorter one; and he is neither more attached nor less individuated than his well counterpart. Among the adolescents with cystic fibrosis, males who know more about their disease are more coping and less defended; males who are more attached are less coping but not necessarily more defended; and these attached males have less dense and extended future time perspectives. Among all the adolescents with cystic fibrosis, those who viewed their illness in a way similar to that of their health care practitioners are somewhat more likely to be coping.

This is the descriptive picture of the adolescent with cystic fibrosis that emerges from this study (a picture of the male adolescent emerging more consistently than that of the female adolescent). One now has to ask what these findings mean for development and for the adjustment and adaptation of the adolescent with cystic fibrosis.

General Discussion and Future Research

These findings answer some questions and raise a number of other questions. These unanswered questions will be discussed and any possible future research efforts which could help answer them outlined.

It isn't possible to determine whether the greater degree of defensiveness in the adolescents with cystic fibrosis reflects a "disequilibrated" stage, a kind of transition from one stage to another, or whether the effects of their illness interfere with the development of greater coping strategies. The fact that the adolescents with cystic fibrosis do seem to use what are labeled as more primitive defenses might suggest that these defenses are not consolidated and do not function smoothly to protect the adolescent. This finding argues against a theory that has been proposed, a

psychological innoculation theory, which would suggest that because of their illness, these children have had to learn how to be more coping and resilient. It may be that a behavioral measure of coping would lead one to different conclusions about the adolescents in this study. But based on the findings in this study derived from a measure originally adapted from a personality inventory, these adolescents are not more coping. To investigate this problem further, one would need a subjective measure of anxiety and a behavioral measure of social adaptation (for example, ratings by parents and teachers). One might then see how the descriptive pattern of ego processes emerging from this study is actually experienced by these children. These additional measures might then help one understand whether the 'defensive' processes described in this study are indeed 'coping' processes, although the findings in this study do not support this notion.

Does the shorter future time extension represent a defensive turning away from the future or does it imply a more realistic understanding of some of the limitations imposed by cystic fibrosis on the life span and thus represent a "reconciliation" between the disease and the adolescent. One might have wanted to include a more direct measure of whether these adolescents anticipated a shorter life span and whether they clearly envisioned an earlier death. Sabatini and Kastenbaun (1973) asked adolescents in college to talk directly about their notions of their own deaths. However, among a group of children with a life-threatening disease, this is often a difficult issue to study since it raises many reasonable objections by parents, practitioners and research guidance committees. Rather than addressing this issue directly, the present study tried to infer what the adolescents might be thinking

about dying and the effects of cystic fibrosis on their life span. This was clearly one of the shortcomings of this study.

How can one explain the insignificant results on the attachment and individuation measures when comparing well adolescents and adolescents with cystic fibrosis? While the theoretical literature and some of the empirical literature would suggest that adolescents with cystic fibrosis are more attached and less individuated, one study (Kellerman et. al. 1980) found that the adolescent with cystic fibrosis (as well as diabetes) feels he has some measure of control over his disease through the influences of diet and exercise. Therefore he does not feel as helpless and dependent as some children with other kinds of disease for which there is less active treatment. It may be that medical practitioners should work with adolescents with cystic fibrosis around those particular aspects of the treatment over which the adolescents can exert control and autonomy.

Adolescents with cystic fibrosis do have higher absolute mean scores on the measure of individuation than the well adolescents (although this difference does not approach statistical significance and the variance on this variable is great). One could ask, however, whether the adolescent with cystic fibrosis is more individuated than his well counterpart. That question can't be definitively answered because there were no significant differences between the two groups. However, if adolescents with cystic fibrosis were found to be significantly more individuated, this finding would lend support to the psychological innoculation theory. It would imply that the experience of having cystic fibrosis, and the kinds of issues these children with cystic fibrosis have had to face at a very early age might have

propelled them towards an earlier individuation and adulthood. While the findings in this study were not conclusive, it might still be an area to look at further in subsequent research studies.

One final formulation about adolescence and cystic fibrosis that takes into account most of the major research variables included in this study will be proposed. It differs from the original formulation proposed by incorporating some of the findings from this study. It may be that adolescence, with its increasing push towards individuation, brings the adolescent with cystic fibrosis into greater contact with concerns about the future and death (and perhaps cystic fibrosis propels the adolescent towards individuation even more quickly). This leads to a greater defensive stance and to a less extended future time perspective. Thus, this study ends with a new formulation or question. The findings are not conclusive in a number of areas but they do not support the notion that the experience of having cystic fibrosis has strengthened or 'innoculated' these children. The findings show them to be less coping and to have less far reaching projections of themselves into the future, but at the same time, they were neither more attached nor less individuated than the well adolescents. Thus, while there is no evidence to support a theory of psychological innoculation, there is also no direct evidence to support the notion that these adolescents are having particular difficulty with the developmental task of individuation and separation.

In conclusion, this study points the way for future research efforts. It has made some specific suggestions for subsequent research projects. Additionally, it has made recommendations for health care providers who work with this particular group of adolescents.

APPENDICES

Appendix A

Age Distributions for Male and Female Adolescents with and without Cystic Fibrosis

Age	Frequency	Age	Frequency
Females with Cystic Fibrosis		**Males with Cystic Fibrosis**	
14	3	14	2
15	2	16	5
16	4	17	1
20	1	18	2
X = 15.60 S.D. = 1.77		X = 16.10 S.D. = 1.37	
Var. = 3.156		Var. = 1.87	
Females without Cystic Fibrosis		**Males without Cystic Fibrosis**	
14	2	15	3
15	1	16	5
16	2	18	2
17	3		
18	2		
X = 16.20 S.D. = 1.47		X = 16.10 S.D. = 1.10	
Var. = 2.178		Var. 1.21	

Appendix B

Separation Anxiety Test

Appendix B

THE SEPARATION ANXIETY TEST

Directions to the Examiner

Be sure to have a room that is undisturbed by outsiders. Have the child sit opposite to you. The book containing the pictures and the statements should be placed directly in front of the child while you have the instructions for the child in front of you. In addition, you should have the recording chart in front of you.

On the chart write the name of the child, the child's age, boy or girl, date of the test, and the name of the facility in which the child is living. It would also be useful to have the number of years in which the child has been living in this facility written on the chart.

Read the instructions to the child and then have the youngster open the book and to the first picture. Tell him (her) to read the title under the first picture and to study the picture. Then call his attention to the printed page opposite the picture. Tell him to read the title at the top of the page. Then ask him to read the questions aloud as follows:

Did this ever happen to you? Yes_____ No_____
If it didn't, can you imagine how it would feel if it did? Yes_____ No_____

Record "Y" for "Yes" and "N" for "No" directly under the Roman numeral. Then say,

The child feels—

and repeat to him to select as many statements below which tell how the child feels. Now indicate that he can read the statements to himself and tell you the number of the statements which he has selected. Encircle these numbers under the appropriate Roman numeral for the picture. Proceed in this same manner for each picture and for each page of statements.

During the examination it is important not to prompt the child in any way. You must, however, remind him that for each picture he should be sure to start out reading the statements at the top and read them in order down the page. It is important that you encircle the numbers under the proper picture, otherwise the test will be invalidated. If the child asks any questions, simply reassure him to use his own judgment and to indicate which statement or statements he thinks apply to the child's feelings. If the child selects only one statement on a particular picture, remind him that he may select as many of the phrases he may wish. Should the child be unable to find any applicable statement, ask him to explain in his own words how the child feels and record this on the back of the chart with the appropriate number for the picture. Our experience has shown that this will rarely ever happen.

When you have completed the administration of the test and dismissed the child, it would be helpful to record your observations of the child's behavior on the back of the chart.

Directions to the Child

This is not a test. It is an experiment to find out what young people feel about some pictures that we have. There are no right or wrong answers. We are only interested in the way you feel about the pictures.

I am going to show you the pictures one at a time. For each picture there will be a number of statements about the child in the picture. You will be asked to pick out as many statements as you wish that tell how the child feels.

Now let's begin with the first picture.

Directions for Adults

This is not a test nor are there any right or wrong answers. We are only interested in the way you felt or, the way you would have felt, if you had been the child in each of the pictures we are about to present to you. In other words we are asking you to imagine that you are a child and to react as if the situation had occurred or might have occurred when you were a child. For each picture there will be a number of statements about the child in the picture and you will be asked to select as many statements as you wish which indicate how the child feels. You merely have to read them to yourself and report aloud the numbers next to the statements you have selected. Now let us begin with the first picture.

THE GIRL WILL LIVE PERMANENTLY WITH HER GRANDMOTHER AND WITHOUT HER PARENTS

THE GIRL WILL LIVE PERMANENTLY WITH HER GRANDMOTHER AND WITHOUT HER PARENTS

Did this ever happen to you? Yes _____ No _____

If it never happened to you, can you imagine how this child feels?
Yes _____ No _____

Check off below as many statements as you think tell how the girl feels.

The Girl Feels

1. that she will be much happier now.
2. that her parents don't love her any more.
3. like curling up in a corner by herself.
4. a terrible pain in her chest.
5. alone and miserable.
6. that she dosen't care what happens.
7. that she will do her best to get along.
8. that this house will be a scary place to live in.
9. that something bad is going to happen to her now.
10. that it's all the fault of her neighbors.
11. angry at somebody.
12. that she won't be the same person any more.
13. that if she had been a good girl, this wouldn't have happened.
14. that it's only a dream—it isn't really happening.
15. like reading a book, watching TV or playing games.
16. sorry for her parents.
17. she won't be able to concentrate on her schoolwork.

A GIRL IS BEING TRANSFERRED TO A NEW CLASS

A GIRL IS BEING TRANSFERRED TO A NEW CLASS

Can you remember when this last happened to you? Yes _____ No _____

Can you imagine how this child feels about it? Yes _____ No _____

Check as many of the statments below which you think tell how this child feels.

This Child Feels

1. that she doesn't care what happens.
2. that the new class is a scary place to be.
3. sorry for her past teacher.
4. that if she had been a good girl, this wouldn't have happened.
5. like playing games with other children.
6. that something is happening to change her.
7. that she make the best of the situation.
8. that nobody really likes her.
9. that now she is going to have a good time.
10. that it's not really happening—it's only a dream.
11. that she won't be able to concentrate on her school work.
12. like sitting alone in the corner of the room.
13. very angry at somebody.
14. like she's getting a stomach ache.
15. alone and miserable.
16. that something terrible is going to happen.
17. that somebody bad is responsible for doing this to her.

THE FAMILY IS MOVING TO A NEW NEIGHBORHOOD

THE FAMILY IS MOVING TO A NEW NEIGHBORHOOD

Did this ever happen to you? Yes _____ No _____

If it didn't, can you imagine how it would feel if it did? Yes _____ No _____

Now try to imagine how the child in this picture feels.
Check off as many statements below which say what you think the child feels.
You may check as many statements as you wish.

The Child Feels

1. afraid to leave.
2. a pain in the stomach.
3. that the neighbors made them move.
4. glad to get away from this bad neighborhood.
5. alone and miserable.
6. that she dosen't care what happens.
7. that it's only a dream.
8. like hiding somewhere.
9. that the new house will be a scary place to live in.
10. that now she will be a different person.
11. that she won't be able to concentrate on her school work.
12. sorry for her parents.
13. that she will make the best of the situation.
14. like punching somebody in the face.
15. that nobody likes her any more.
16. that now she can make some new friends.
17. that if she had behaved in the neighborhood, she wouldn't have to move.

THE CHILD IS LEAVING HER MOTHER TO GO TO SCHOOL

THE CHILD IS LEAVING HER MOTHER TO GO TO SCHOOL

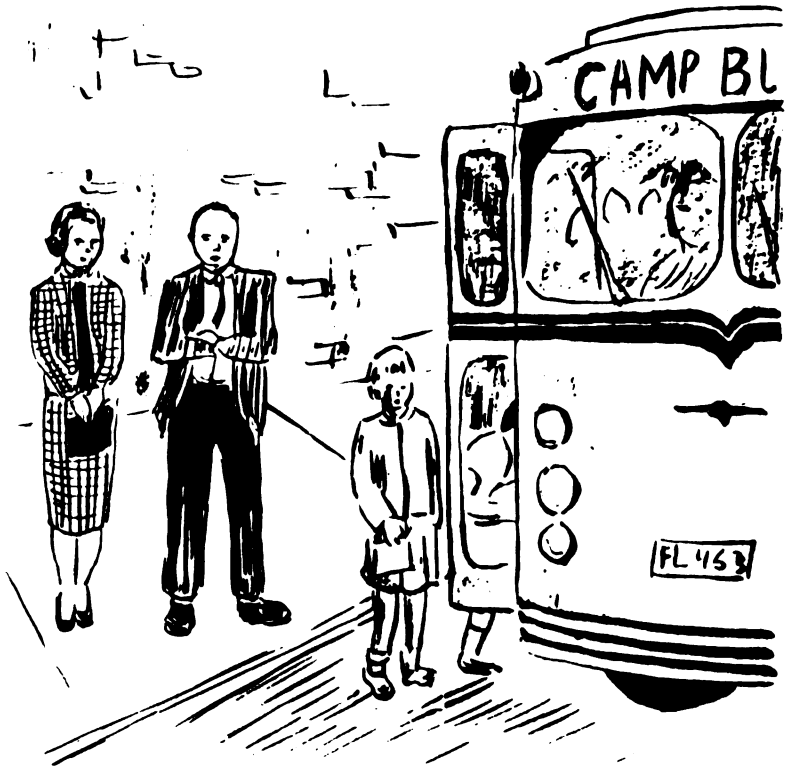
You have done what this girl is doing many times.

You no doubt have some idea about her feelings, don't you?
Yes _____ No _____

Check as many statments below which you think tell how this girl feels.

The Girl Feels

1. that she won't be able to concentrate on her school work.
2. afraid to leave.
3. that school is a scary place to be.
4. that her mother doesn't like her.
5. that she dosen't care what happens.
6. angry at having to go to school.
7. like joining her friends and going to school.
8. glad to get away from her house.
9. sorry for her mother.
10. like she's going to be sick.
11. that something is happening to change her.
12. if she had been a good girl, her mother would let her stay home.
13. like staying home in bed.
14. that she will do her best to get along.
15. that it's not really happening—it's only a dream.
16. alone and miserable.
17. that somebody else is causing all this trouble.



A CHILD IS LEAVING HER PARENTS TO GO TO CAMP

A CHILD IS LEAVING HER PARENTS TO GO TO CAMP

Do you remember if this ever happened to you? Yes _____ No _____

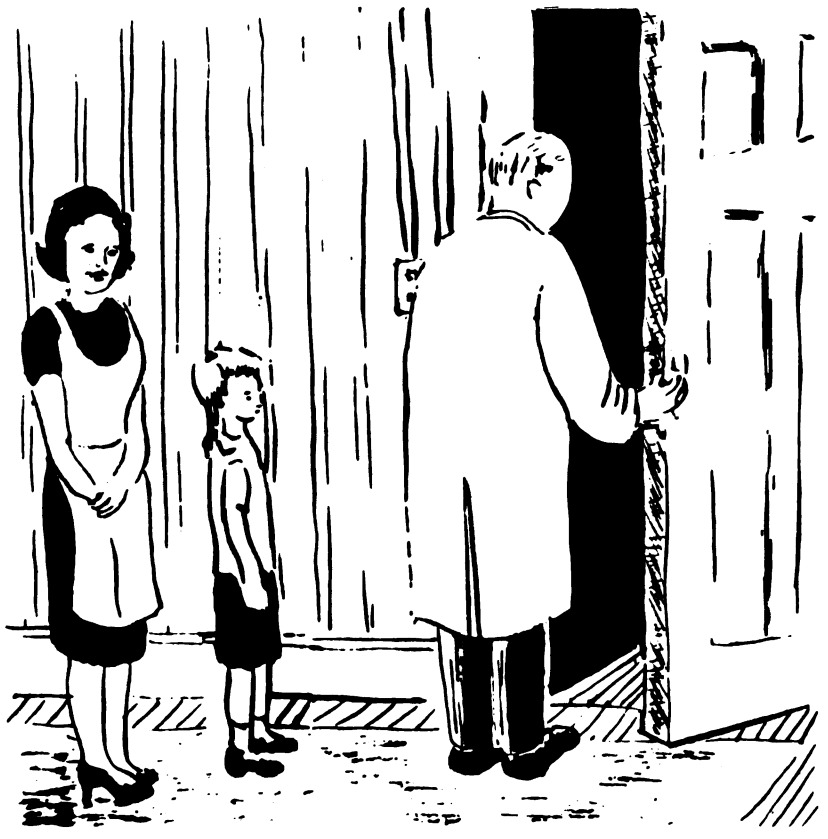
Can you imagine how it felt when it did happen? Yes _____ No _____

If it didn't happen to you, can you imagine how it would feel if it did?
Yes _____ No _____

Now check off as many of the statements below which you think tell what this girl feels.

The Girl Feels

1. sorry for her parents.
2. angry about going.
3. that this is a scary place to be.
4. that now she will be a different person.
5. that it's not really happening—it's only a dream.
6. that her mind can't think straight.
7. like sitting alone in the back of the bus.
8. that someone else made this happen to her.
9. like reading a book and playing games.
10. that she doesn't care what happens.
11. that something terrible is going to happen to her.
12. that a bad headache is coming on.
13. that nobody really loves her.
14. that she will make the best of the situation.
15. that if she had been a good girl, her parent's wouldn't send her away.
16. that now she is really free to enjoy herself.
17. alone and miserable.



AFTER AN ARGUMENT WITH THE MOTHER, THE FATHER IS LEAVING

AFTER AN ARGUMENT WITH THE MOTHER, THE FATHER IS LEAVING

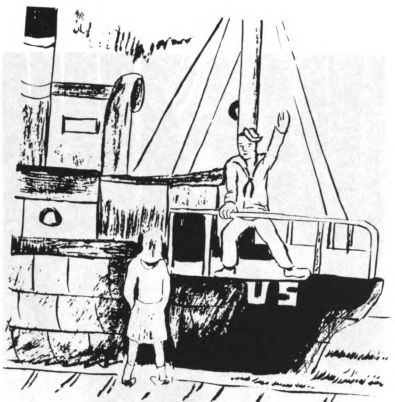
Did this ever happen to you? Yes _____ No _____

If not, can you imagine how you would feel if it did? Yes _____ No _____

Now check off as many of the statements below which tell what you think the girl in the picture feels. Check as many statements as you wish.

The Girl Feels

1. very angry at the father.
2. that now she is free to do anything she wants to.
3. that her home will now be a scary place.
4. that she won't be able to concentrate on her school work.
5. that something terrible is going to happen to her now.
6. that someone else has been causing all of this trouble.
7. like reading a book, fixing something or watching TV.
8. like something is happening to change her.
9. lonely and unhappy.
10. nobody really likes her.
11. that she is going to be very sick.
12. like hiding away in her parent's bedroom.
13. sorry for her mother.
14. that she doesn't care what happens.
15. that she will try hard to work things out.
16. that she, herself, caused her father to leave.
17. that it's only a dream—it really isn't happening.



THE GIRL'S OLDER BROTHER IS A SAILOR LEAVING ON A VOYAGE

THE GIRL'S OLDER BROTHER IS A SAILOR LEAVING ON A VOYAGE

Did this ever happen to you? Yes _____ No _____

Can you imagine how you would feel if this happened to you?
Yes _____ No _____

Now try to imagine how the child in the picture feels.
Check off as many statements below which say what you think the child feels.

The Child Feels

1. sorry for her brother.
2. that if she had behaved better, her brother wouldn't have left her.
3. that it's not really happening—it's only a dream.
4. that this is a very scary thing.
5. very angry.
6. lonely and miserable.
7. that she will not be the same peson any more.
8. like sitting alone in her room at home:
9. that someone else caused all this trouble.
10. like playing a game with her friend.
11. that she won't be able to concentrate on her school work.
12. that she will try hard to work things out.
13. that something terrible is going to happen to her.
14. that nobody really likes her.
15. that a bad stomach ache is coming on.
16. that she doesn't care what happens.
17. that now she is free to enjoy herself in any way she likes.

THE JUDGE IS PLACING THIS CHILD IN AN INSTITUTION

THE JUDGE IS PLACING THIS CHILD IN AN INSTITUTION

Can you remember if this ever happened to you? Yes _____ No _____

If it never happened to you, can you imagine how you would feel if it did? Yes _____ No _____

Now check as many statements below which tell what you think this child feels. Check as many statements as you wish.

The Child Feels

1. that the world is full of bad people who did this to her.
2. that it's only a dream and she will wake up soon.
3. like committing suicide.
4. that she will go and make the best of it.
5. sorry for her parents.
6. that the court room is a frightening place.
7. like curling up in a corner.
8. dizzy and faint.
9. that she doesn't care what happens.
10. happy to get to the institution as soon as possible.
11. that she is not very well liked.
12. terrified at what will happen to her.
13. like reading a book or watching TV.
14. angry at the judge.
15. that now she won't be able to learn school work.
16. all alone and unhappy.
17. that now she will be a different person.

THE MOTHER HAS JUST PUT THIS CHILD TO BED

THE MOTHER HAS JUST PUT THIS CHILD TO BED

This has probably happened to you many times.

Can you imagine in your mind that it is happening right now?
Yes _____ No _____

Now check off those statements below which you think tell how the child feels. Check as many statements as you wish.

The Girl Feels

1. angry at the mother.
2. that it's scary to be alone here.
3. like hiding under the covers.
4. that she doesn't care what happens.
5. that something is happening to change her.
6. that someone in the family made the mother leave.
7. that now she's free to enjoy herself in any way she likes.
8. that her mother doesn't stay with her because she's a bad girl.
9. that it's not really happening—it's only a dream.
10. that she will make the best of the situation.
11. like reading a book, watching TV or making clay models.
12. that something bad is going to happen to her.
13. sorry for her mother.
14. that she is getting sick.
15. that her mother doesn't really like her.
16. that she, won't be able to study in school tomorrow.
17. very lonely.

THE GIRL'S MOTHER IS BEING TAKEN TO THE HOSPITAL

THE GIRL'S MOTHER IS BEING TAKEN TO THE HOSPITAL

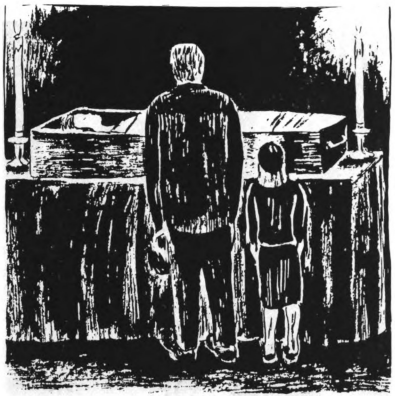
Did anything like this ever happen in your family? Yes _____ No _____

If it didn't, can you imagine how you would feel if it did happen?
Yes _____ No _____

Now check off as many statements below which tell what you think this child feels. Check as many statements as you wish.

The Girl Feels

1. very angry at somebody.
2. that she will not be the same person any more.
3. glad that her mother is leaving.
4. like hiding in her room.
5. that she doesn't care what happens.
6. that it's not really happening—it's only a dream.
7. that she's going to have a bad headache.
8. that she will do her best to get along..
9. scared about what is going to happen to her.
10. sorry for her mother.
11. that nobody likes her any more.
12. like watching TV.
13. that her mother became sick because she was bad.
14. that somebody else caused all this trouble.
15. that her room is going to be a scary place to stay in now.
16. alone and miserable.
17. that she won't be able to concentrate on her school work.



THE GIRL AND HER FATHER ARE STANDING AT THE MOTHER'S COFFIN

THE GIRL AND HER FATHER ARE STANDING AT THE MOTHER'S COFFIN

Did this ever happen to you? Yes _____ No _____

If it didn't, can you imagine how it would feel if it did? Yes _____ No _____

Now try to imagine how the child in the picture feels.
Check off as many statements below which say what you think the child feels.
You may check as many statements as you wish.

The Child Feels

1. that she won't be the same person any more.
2. frightened about what will happen to her.
3. that if she had been a good girl, it wouldn't have happened.
4. that now she is free to do what she wants.
5. angry about what happened.
6. that nobody will love her any more.
7. that she doesn't care what happens.
8. that her home will now be a scary place to live in.
9. like sitting in a corner by herself.
10. that other people are to blame for this.
11. that she will make the best of the situation.
12. that it is only a dream.
13. a bad pain in her head.
14. sorry for her father.
15. alone and miserable.
16. that now she won't be able to study any more.
17. like reading a book or watching TV.

THE GIRL IS RUNNING AWAY FROM HOME

THE GIRL IS RUNNING AWAY FROM HOME

Did you ever do anything like this? Yes _____ No _____

If you didn't, did you ever think of doing something like this?
Yes _____ No _____

Can you understand why this child would want to do this?
Yes _____ No _____

Now check as many of the statements below which you think tell how this child feels.

The Child Feels

1. that she is just going away to have some fun.
2. angry at her parents.
3. afraid that she will be punished for something she did.
4. that she doesn't care what happens.
5. that her parent's don't want her around any more.
6. that the neighbors have been stirring up her parents against her.
7. terrible stomach cramps coming on.
8. that she will do her best to get along.
9. that she is only dreaming about this and it's not happening.
10. that something very bad is going to happen to her.
11. that it is awfully scary outside.
12. sorry for her parents.
13. like watching TV or reading a book.
14. like going to her hideout.
15. that she won't be able to study school work any more.
16. that now she will be a different person.
17. lonely and miserable.

Appendix C

Incomplete Sentences Test

Complete each sentence by putting a number in the blank space. Write in the number that makes the sentence true for you.

1. I often think of what I will do within the next _____ year(s).
2. Sometimes I wonder what I will be like when I am _____ years old.
3. I have very clear plans for the next _____ year(s).
4. I have planned a few things as much as _____ year(s) ahead.
5. I don't see much sense in planning more than _____ year(s) ahead.
6. I hope I will have gotten most of the things I want out of life by the time I am _____ years old.
7. Being _____ years old is so far away that I haven't thought much about what I will do then.
8. I like best thinking about when I will be _____ years old.
9. I often think of what I will do when I am _____ years old.

Appendix D

Events Test

Directions: Different people have different notions of when things will occur to them in their lives. I would like to ask you when you think particular events will happen to you. I am going to read you a series of sentences and would like you to give me the age that makes the sentence true for you.

1. You have reached middle age _____.
2. Your first child is born _____.
3. You get a place of your own _____.
4. You are too old to be physically active _____.
5. You get your first full-time job _____.
6. You marry _____.
7. You finish school _____.
8. Your mother dies _____.
9. You can say that you have most of the things you want _____.

Appendix E

Statistical Properties of the Ego Scales

Appendix E

Means and standard deviations:

student subjects

	Males		Females	
CPI based scales	Mean	SD	Mean	SD
Objectivity	19.74	2.97	17.03	2.32
Isolation	13.73	2.47	13.88	2.56
Intellectuality	17.60	3.79	17.73	3.59
Intellectualization	18.28	3.97	16.14	4.05
Logical analysis	16.25	3.78	16.44	2.48
Rationalization	12.47	2.70	13.04	2.90
Concentration	21.18	2.48	20.78	2.69
Denial	18.15	3.14	20.12	3.73
Tolerance ambiguity	20.88	3.74	18.33	3.36
Doubt	9.68	4.88	14.41	5.20
Empathy	18.88	2.57	18.88	2.55
Projection	11.25	3.37	7.69	2.37
Regression ego	15.85	3.55	15.47	3.52
Regression	12.32	3.71	12.26	3.78
Sublimation	22.34	2.79	23.04	2.69
Displacement	13.04	4.06	10.64	3.33
Substitution	20.44	2.63	18.78	2.72
Reaction formation	16.88	2.17	13.66	2.93
Suppression	23.36	3.11	23.65	2.53
Repression	15.21	3.13	13.86	3.21
Summed coping	19.76	2.91	19.28	2.82
Summed defense	13.83	2.97	10.59	2.84
Controlled coping	26.83	4.47	21.47	3.77
Expressive coping	19.73	4.16	18.99	3.20
Structured defense	23.05	3.75	16.72	4.07
Primitive defense	11.21	3.18	14.13	3.74

Note: CPI sample size: Males N = 95; Females N = 108

(Haan, 1977, p. 323)

Appendix E

Means and standard deviations:

adult subjects

	Males		Females	
CPI based scales	Mean	SD	Mean	SD
Objectivity	20.68	4.06	16.39	3.14
Isolation	13.90	3.22	12.83	2.70
Intellectuality	17.34	5.16	15.69	5.14
Intellectualization	18.76	5.52	14.05	4.74
Logical analysis	16.28	4.34	15.07	3.43
Rationalization	12.33	3.20	13.61	3.49
Concentration	21.65	3.54	19.95	3.20
Denial	18.62	4.26	19.98	4.10
Tolerance ambiguity	18.20	4.66	16.47	4.88
Doubt	8.22	5.41	13.36	6.03
Empathy	18.73	3.51	19.48	3.13
Projection	10.61	3.83	7.69	2.82
Regression ego	13.66	4.42	14.40	4.49
Regression	10.29	4.92	11.59	4.54
Sublimation	22.04	2.86	22.45	3.40
Displacement	11.82	4.48	9.48	4.56
Substitution	20.32	3.07	17.11	3.61
Reaction formation	18.95	3.78	14.80	4.13
Suppression	23.77	3.62	24.41	3.21
Repression	15.07	3.64	14.90	4.22
Summed coping	18.42	3.83	18.49	3.81
Summed defense	12.75	3.63	10.10	3.46
Controlled coping	28.49	5.65	19.43	4.91
Expressive coping	18.99	5.64	17.83	4.43
Structured defense	21.99	4.98	15.61	5.44
Primitive defense	10.59	4.93	15.56	5.04

Note: CPI sample size: Males N = 111; Females N = 132.

(Haan, 1977, p. 322)

Appendix E

Validity Coefficients of the Ego Scales

	Coping			Defense	
	Male	Female		Male	Female
CPI based scales					
Objectivity	.29	.25	Isolation	.28	.39
Intellectuality	.57	.44	Intellectualization	.37	.38
Logical analysis	.53	.41	Rationalization	-	.21
Concentration	-	-	Denial	.21	.57
Tolerance of ambiguity	.42	.43	Doubt	.36	.44
Empathy	.34	.22	Projection	.42	.24
Regression-ego	.38	.32	Regression	.31	.39
Sublimation	-	.23	Displacement	.29	.49
Substitution	.25	-	Reaction formation	.46	.31
Suppression	-	-	Repression	.34	.38
Total coping	.49	.36	Total defense	-	.35
Controlled coping	.29	.27	Structured defense	-	.47
Expressive coping	.20	.24	Primitive defense	.27	.40

(Haan, 1977, p. 284)

Appendix E

Factor Analysis of Ego Processes

	Factor Loadings							
	Factor 1		Factor 2		Factor 3		Factor 4	
	Male	Female	Male	Female	Male	Female	Male	Female
Objectivity	.74	.64	.34	.34	-.15	-.19	-.16	-.31
Isolation	-.02	-.01	-.52	-.38	.58	.66	.19	.20
Intellectuality	.72	.74	.47	.38	.07	.08	-.09	-.19
Intellectualization	.39	.32	.02	-.10	.74	.75	.17	.04
Logical analysis	.70	.74	.44	.38	-.07	-.15	-.23	-.25
Rationalization	-.21	-.23	-.22	-.10	.66	.70	.28	.06
Concentration	.69	.70	.12	-.03	-.06	-.20	-.48	-.09
Denial	-.30	-.36	-.46	-.09	.33	.10	-.18	.70
Tolerance of ambiguity	.38	.54	.65	.27	-.12	.05	.12	-.45
Doubt	-.07	-.36	-.09	.19	.27	.58	.80	-.02
Empathy	.16	.23	.75	.77	-.04	-.13	-.19	-.25
Projection	-.47	-.18	-.15	-.24	.61	.58	-.04	.36
Regression-ego	.17	.33	.79	.65	-.07	-.02	-.05	-.21
Regression	-.51	-.32	.15	.07	.43	.77	.49	.16
Sublimation	.15	.12	.44	.18	-.01	-.30	-.53	-.18
Displacement	-.61	-.15	-.15	-.25	.46	.60	.01	.15
Substitution	.71	.62	.17	.33	.04	-.19	.01	.19
Reaction formation	-.11	.12	-.56	-.10	.47	.30	.11	.73
Suppression	.40	.25	.51	.67	-.26	-.40	-.10	-.05
Repression	-.18	-.34	-.74	-.32	.11	.16	.13	.67

Males, N = 175; females, N = 188. The following labels were offered for the factors: factor 1, controlled coping; factor 2, expressive coping; factor 3, structured defenses, factor 4, primitive defenses.

(Haan, 1977, p. 286)

Appendix F

Cystic Fibrosis Questionnaire

CIRCLE EITHER TRUE OR FALSE:

1. Enzymes need to be taken with snacks. T or F
2. Under some circumstances, cystic fibrosis may be contagious. T or F
3. If you are not coughing, you don't need postural drainage. T or F
4. Something a mother eats during her pregnancy may contribute to her giving birth to a child with cystic fibrosis. T or F
5. If there is fresh blood in the sputum, the doctor should be called. T or F
6. Snacks between meals are to be avoided. T or F
7. More sputum means one is getting better. T or F
8. Jogging is bad for people with cystic fibrosis. T or F
9. Carriers of cystic fibrosis can be detected by the sweat test. T or F
10. Low salt levels cause weakness and nausea. T or F
11. You can stop taking antibiotics once you begin feeling better. T or F
12. A brother or sister of a person with cystic fibrosis has a 25% chance of having cystic fibrosis. T or F
13. One can diagnosis cystic fibrosis by listening to chest sounds. T or F
14. Large, bulky bowel movements are caused by not enough pancreatic enzymes. T or F
15. Cystic fibrosis is caused by genetic inheritance. T or F

Appendix G

Shwachman Scale

CLINICAL EVALUATION AND GRADING CRITERIA FOR PATIENTS WITH CYSTIC FIBROSIS

POINTS	CASE HISTORIES	PULMONARY PHYSICAL FINDINGS AND COUGH	GROWTH AND NUTRITION	CHEST X-RAY
25	Full activity Normal exercise tolerance and endurance Normal motor development Normal personality and disposition Normal school attendance	No cough Normal pulse and respiration No evidence of overinflation Lungs clear to auscultation Good posture No clubbing	Maintains weight and height above twenty-fifth percentile or compatible with familial pattern Good muscle mass and tone Normal subcutaneous fat Normal sexual maturation Good appetite Well formed almost normal stools	No evidence of overinflation No increase in markings No infiltration or atelectasis
20	Slight limitation of strenuous activity Tires at end of day or after prolonged exertion Less energetic Low normal range of motor development Occasionally irritable or passive Good school attendance	Occasional hacking cough Clearing of throat Resting pulse and respiration normal Mild overinflation Occasional, usually localized harsh breath sounds, rhonchi, or prolonged expiratory phase Good posture clubbing± to 1+	Maintains weight and height above 10th percentile or slightly below familial pattern Good muscle mass/tone Slightly decreased subcutaneous fat Slightly retarded sexual maturation Normal appetite Stools more frequent and slightly abnormal	Minimal evidence of overinflation Mild accentuation of bronchovascular markings No infiltration or atelectasis
15	May rest voluntarily Tires after exertion Fair school attendance Moderately inactive Slight motor retardation Lacking spontaneity Passive or irritable	Mild chronic nonrepetitive cough in the morning on arising, after exertion or crying, or occasionally during the day No night cough Respiration and pulse slightly elevated Increased A-P diameter and depressed diaphragms Coarse breath sounds Occasional localized rales, rhonchi, or wheezes Moderate rounding of shoulders 1-2+ clubbing	Maintains weight and height above 3rd percentile or moderately below familial pattern Weight usually deficient for height Fair muscle mass/tone Moderate deficiency of subcutaneous fat Abdomen slightly distended Maturation definitely retarded Fair appetite Stool usually abnormal, large, floating, occasionally foul but formed	Moderate overinflation Increased A-P diameter Lung fields more radiolucent Diaphragms moderately depressed Increased bronchovascular markings Localized or patchy atelectasis Occasional transient infiltration
10	Limited physical activity and exercise tolerance Dyspneic after exertion Moderate motor retardation Fussy, irritable, sluggish, or listless Poor school attendance, may require home tutor	Chronic cough, frequent, repetitive, productive, and rarely paroxysmal Respiration and pulse moderately elevated Moderate to severe overinflation often with chest deformity Rales, rhonchi, or wheezing usually present and often widespread Rounded shoulders and forward head Clubbing 2-3+ Usually cyanosis	Weight and height below 3rd percentile Weight deficient for height Poor muscle mass/tone Marked deficiency of subcutaneous fat Moderate abdominal distention Failure of sexual maturation and no adolescent growth spurt Poor appetite Stools poorly formed, bulky, fatty and foul smelling	Marked overinflation Marked increase in A-P diameter Diaphragms markedly depressed Narrow cardiac silhouette Occasional localized segmental or lobar atelectasis Persistent foci of infiltration Localized cysts Marked increase in markings
5	Severe limitation of activity Dyspnea and orthopnea Inactive or confined to bed or chair Marked motor retardation Apathetic or irritable Cannot attend school	Severe paroxysmal, frequent, productive cough often associated with vomiting or hemoptysis Night cough Tachypnea/tachycardia Barrel chest Generalized fine and coarse rales, rhonchi, musical wheezes Poor posture 3-4+ clubbing Cyanosis	Malnourished and stunted Weak, flabby, small muscles Absence of subcutaneous fat Large, flabby, protuberant abdomen Failure to grow or gain, often with weight loss Bulky, frequent, foul, fatty stools Frequent rectal prolapse	Extensive changes Severe overinflation Lobar or widespread atelectasis and infiltration Widespread cyst formation Bronchiectasis and abscess formation

From: Guide to Diagnosis and Management of Cystic Fibrosis, A Syllabus for Physicians. Prepared by the Professional Education Committee, Cystic Fibrosis Foundation, December, 1979.

APPENDIX H

Correlation Coefficients between Attachment and Individuation Percentages and Measures of Future Time Extension Among Adolescents With and Without Cystic Fibrosis

	Adolescents with Cystic Fibrosis			Adolescents without Cystic Fibrosis		
	N=20	Males N=10	Females N=10	N=20	Males N=10	Females N=10
Attachment % Correlated With:						
Density	-.13	-.55*	.17	-.35+	-.37+	-.26
Extension:						
Incomplete Sentences	.05	-.08	.12	-.41*	-.33	-.46+
Events Test	.14	.07	.35	-.33+	-.37	-.16
Individuation % Correlated With:						
Density	-.11	.45+	-.25	-.25	.50+	.37
Extension:						
Incomplete Sentences	-.05	-.15	.18	.13	-.21	.54*
Events Test	.70*	.75*	.50+	.07	-.29	.66*

*Significant at $<.05$ level.
+Approaches significant at $<.10$ level.

APPENDIX I

Correlation Coefficients Between Future Time Extension, Individuation And Attachment Percentages and Ego Processes for Adolescents Without Cystic Fibrosis.

	Adolescents without Cystic Fibrosis		
		Females	Males
	N=20	N=10	N=10
Incomplete Sentences Extension Correlated With:			
Summed Coping	.14	.36	-.28
Summed Defense	-.14	-.49+	.02
Controlled Coping	.28	.72*	-.27
Expressive Coping	.22	.62*	-.44+
Structured Defense	-.12	-.60*	.10
Primitive Defense	-.39*	-.65*	-.10
Events Test Extension Correlated With:			
Summed Coping	.36*	.37	.26
Summed Defense	-.06	.02	-.25
Controlled Coping	.36*	.43+	.32
Expressive Coping	.07	.21	-.22
Structured Defense	.18	.12	.02
Primitive Defense	-.24	-.36	-.10
Individuation Correlated With:			
Summed Coping	.36*	.17	.48
Summed Defense	-.37*	-.30	-.44
Controlled Coping	.35	.45+	.28
Expressive Coping	.09	.51+	-.30
Structured Defense	-.01	-.08	.02
Primitive Defense	-.58*	-.63*	.56
Attachment Correlated With:			
Summed Coping	-.26	-.23	-.28
Summed Defense	.33+	.48	.27
Controlled Coping	-.43*	-.52	-.34
Expressive Coping	-.07	-.23	.14
Structured Defense	.23	.47+	.15
Primitive Defense	.41*	.54*	.29

*Significant at $<.05$ level.

+Approaches significance at $<.10$ level.

APPENDIX J

Correlation Coefficients Between Future Time Extension, Individuation and Attachment Percentages and Ego Processes for Adolescents With Cystic Fibrosis.

	Adolescents with Cystic Fibrosis		
	N=20	Males N=10	Females N=10
Incomplete Sentences Extension Correlated With:			
Summed Coping	.05	.12	.06
Summed Defense	.06	.23	-.15
Controlled Coping	.18	.23	.24
Expressive Coping	-.26	-.08	-.46+
Structured Defense	-.13	-.17	-.08
Primitive Defense	.12	-.06	.42
Events Test Extension Correlated With:			
Summed Coping	.14	.08	.25
Summed Defense	.03	-.27	.47+
Controlled Coping	.24	.15	.37
Expressive Coping	-.04	-.04	-.39
Structured Defense	-.05	-.15	.13
Primitive Defense	-.05	-.13	.06
Individuation Correlation With:			
Summed Coping	.07	.14	-.18
Summed Defense	.09	-.14	.34
Controlled Coping	.06	.01	-.03
Expressive Coping	.12	.12	-.11
Structured Defense	-.05	-.10	-.08
Primitive Defense	-.01	-.21	.31
Attachment Correlated With:			
Summed Coping	-.18	-.55*	.09
Summed Defense	.08	.34	.04
Controlled Coping	-.29	-.66*	.13
Expressive Coping	-.62*	-.86*	-.53*
Structured Defense	.24	.30	.26
Primitive Defense	.08	.20	.02

*Significant at $<.05$ level.

+Approaches significance at $<.10$ level.

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