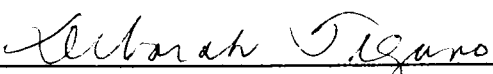
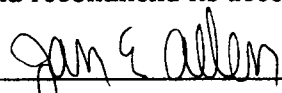
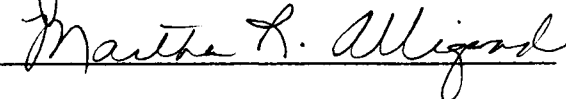


To the Graduate Council:

I am submitting herewith a thesis written by Nicole Graham entitled "The Experiences of Adolescents Living with Cystic Fibrosis." I have examined the final copy of this thesis for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Master of Science, with a major in Child and Family Studies.


Deborah Tegano, Major Professor

We have read this thesis
and recommend its acceptance.

Accepted for the Council:


Associate Vice Chancellor and
Dean of The Graduate School

THE EXPERIENCES OF ADOLESCENTS LIVING
WITH CYSTIC FIBROSIS

A Thesis
Presented for the
Master of Science
Degree
The University of Tennessee, Knoxville

Nicole Marie Graham
December, 1998

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DEDICATION

This thesis is dedicated to my parents, John and Melissa Graham, who always believed I would find my place in the world. It is their encouragement that inspires me to reach for my very best.

iii
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iv
ABSTRACT

The purpose of this study was to describe the experience of being an adolescent living with cystic fibrosis. The beginning foundations of this study were in Piaget's theory of cognitive development, Erikson's theory of psychosocial development, and Rogers' theory on becoming a person. It was projected that the adolescents would be able to understand that the disease is terminal and that they would experience psychosocial difficulties associated with the illness and their stage of development.

Six adolescents were recruited from a local children's hospital and participated in interviews in their homes. They were between the ages of 11 and 16 years. The interviews were phenomenological and the main question was "When are some times you are aware of having cystic fibrosis?" The interviews were analyzed by two separate research groups. Three themes, Similarities/Differences, Doing/Stopping, and Support, emerged from the data against the grounds of Body, Time, and Others.

Examples from each theme illustrated that the adolescents did have psychosocial difficulties. They were concerned about such things as not fitting in with their peers, an uncertain future, and their bodies failing them during activities and social interactions. It was also discovered, however, that these adolescents had healthy coping mechanisms such as disassociating their "selves" from the illness, not directly discussing death, and utilizing extensive support systems. These stressors and coping mechanisms were interpreted in a holistic manner using Neuman's Systems Model to consider physiological, psychological, sociocultural, spiritual, and developmental responses to stress. The developmental stage of adolescence emerged as a particularly important variable in the lived experience of the participants. In addition to describing the experience of being an adolescent living with cystic fibrosis, ideas for future research and uses for the current research were presented.

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CHAPTER I

INTRODUCTION

As treatments for cystic fibrosis improve, there is an ever-growing population of adolescents and young adults living with the disease. These young people are at a developmentally difficult stage to begin with, and living with a terminal illness presents them with additional problems. In order to care appropriately for these adolescents, it is important to understand the experience of being chronically ill from their perspective. The purpose of this study was to describe the experience of being an adolescent living with cystic fibrosis.

It is suspected that in addition to treating the illness, these adolescents will experience other psychosocial concerns related to the illness and to their stage of development. These teens are hoping to form an individual identity just like their healthy peers, but the enforced dependence caused by the illness may hinder that. Also, they are coping with issues such as a potentially early death that their healthy peers do not think about. These adolescents are faced with many differences from their peers and must learn to cope with them.

This study will describe the lived experience of being an adolescent with cystic fibrosis. In doing so, it is possible to gain insight into how caregivers can be most effective in providing treatment, encouraging compliance, and providing support.

CHAPTER II

REVIEW OF LITERATURE

Cystic Fibrosis

Cystic fibrosis is an inherited terminal disease that affects the gastrointestinal tract, the pancreas, and the respiratory tract. The diagnosis is usually made shortly after birth. "The name cystic fibrosis (CF) describes the changes that occur at an early age in the pancreas of CF patients....The part of the pancreas that produces digestive enzymes (proteins that digest food) is replaced by characteristic fibrous scar tissue with fluid-filled spaces (cysts)" (Harris & Super, 1995, p.1). In addition to this change, increased and unusually thick mucous secretions in the lungs and digestive system cause oxygen deprivation and malabsorption of nutrients leading to breathing difficulties and growth failure. Other symptoms of cystic fibrosis include a chronic productive cough, recurring lung infections, ravenous appetite, clubbing of the fingers, and reduced physical stamina (Docter, 1973; Burton, 1975; Waddell, 1983).

People living with CF require daily doses of medications and chest therapy. They must take enzymes to digest their food and are often on antibiotics to clear up and prevent lung infections. Forms of treatment include aerosol inhalations and vibrating vests to break up mucous in the chest. These therapies are often repeated several times each day. In addition, care and cleaning may be required to maintain central lines (long term IVs) and feeding tubes. This daily regimen of care continues throughout the patient's lifetime. At this time, heart-lung transplants offer the best hope for continued survival. These transplants can add years to a patient's life expectancy but are not a cure.

Cystic fibrosis is often diagnosed by sweat tests, as CF sufferers have increased levels of salt in their sweat. The disease must be inherited from both the mother and the

father. "Cystic fibrosis is the commonest autosomal recessive genetic disease of white Indo-Europeans (Caucasians). In most parts of the world, between 1 in 1500 and 1 in 2500 Caucasian children are born with CF, although the disease may not be apparent at birth. If one takes these two sets of frequencies then between 1 in 16 and 1 in 25 Caucasians is a carrier" (Harris & Super, 1995, p.4). Research groups discovered the location of the gene causing CF in 1985, but it was not until 1989 that the gene was isolated. These discoveries have made it possible to identify carriers of the gene and to identify very early on the children who will have the disease, but the disease remains incurable (Harris & Super, 1995; Whyte, 1994). Improved methods of treatment have increased life expectancy significantly and those who might have died during early childhood are now living into young adulthood. This presents new challenges for caregivers as well as for those living with the disease. "As more patients with cystic fibrosis are reaching adulthood, it has become important to assess psychological performance and to determine how these patients can best be helped to function well" (Boyle, Sack, Millican & di Sant'Agnese, 1973, p.385).

Adolescent Development--Cognitive and Psychosocial

In order to assess the psychological state of adolescents living with a chronic illness, and the meaning they attribute to living with that illness, it is necessary to understand both typical adolescent development and the additional issues that may be raised because of the illness. A starting point is to explore how children conceptualize illness. An understanding of how children develop their conceptions of illness can be found by exploring Piaget's theoretical framework of intellectual development. Piaget (1929) has shown that children of different ages think qualitatively differently and that their thinking progresses through several discrete stages. These stages are sensori-motor (0-2 years), preoperational (2-7 years), concrete operational (7-11 years), and formal operational (over 12 years).

In the sensori-motor stage, children explore their world in terms of their bodies. Children explore through movement, touch, and taste. This is a time when the child distinguishes himself from the environment through bodily senses. Preoperational children are beginning to use language, and therefore a symbol system, but they still have difficulty understanding anything that is not part of their direct experience. These children are egocentric, and can only comprehend one aspect of an experience at a time. As the children move into the concrete operational stage, they begin to use basic logic to understand more than one aspect of an experience at a time, but only if it involves some concrete object or experience with which they are familiar. The understanding or application of ideas to fantasy situations is still beyond the operational child's ability. The formal operational child has the ability to think about abstract or imaginary situations and ideas. This child can generalize ideas from one situation to the next, and is not restricted to concrete items that can be seen and touched. The formal operational child thinks logically as well as empirically.

Based on Piaget's framework of cognitive development, it is reasonable to suppose that children of different ages would have different conceptions of illness. The literature suggests two ways of understanding the development of children's conceptions -- as a product of the child's family's beliefs concerning illness and health history (Campbell, 1975; Caradang, Folkins, Hines & Steward, 1979), as well as simply being consistent with the child's cognitive level (Neuhauser, Amsterdam, Hines & Steward, 1978; Bibace & Walsh, 1980; Perrin & Gerrity, 1981).

The studies investigating the effect of familial understandings of illness on children's understandings indicate that although children share ideas similar to those of adults, the parental views are not significant predictors of the child's understanding (Campbell, 1975). Campbell (1975) interviewed 264 hospitalized children and their mothers and determined that although the mothers' understanding of illness did not predict

the children's understanding, the children's ages and health histories did influence their conceptualizations of illness. Younger children with poor health were found to have less organized understandings of illness, and older children had more sophisticated conceptions. This study implies an agreement that cognitive level (indicated by age differences) affects children's understandings of illness.

Similarly, the study by Caradang, et al. (1979) investigated the effects of having an ill sibling in the home on a child's understanding of illness. Seventy-two children, ages 6 1/2 to 15 years, and their mothers were interviewed. The results were "that illness conceptualization generally followed a Piagetian developmental sequence" (Caradang, et al., 1979, p.480). Also, children with ill siblings were found to have poorer understandings of illness than their overall cognitive level would have suggested. It is possible that the stress of living with an ill sibling caused the children to perform at lower cognitive levels on the illness conceptualization measures.

The studies focusing mainly on the potential link between conception of illness and Piagetian developmental stages provide more conclusive evidence that there is, in fact, such a link. Neuhauser, et al. (1978), administered Piagetian conservation tests and questionnaires about healing concepts to 24 children ages 4-5 years and 8-9 years. The younger preoperational children were found to believe they had less control over healing than did the concrete operational children. Also, the "cognitive level influenced the sophistication of the answer given" (Neuhauser, et al., 1978, p. 341) concerning the functions of the inside of the body during healing.

Bibace and Walsh (1980) hypothesized that children's understandings of illness, its causes, and its cures would match Piaget's (1930) findings about the development of causal reasoning. Children at the preoperational (4 years), concrete operational (7 years), and formal operational (11 years) stages were interviewed about several types of illness as

well as about causal thinking in general. The study supported the notion of the existence of a developmental sequence consistent with Piaget's findings and also suggested that the children's ideas about how much control they have over the illness changes as the developmental category changes.

Perrin and Gerrity (1981) accepted that development of conceptualizations of illness occur in a way consistent with Piaget's cognitive stages. They chose to investigate the rate of the developmental process, and what kinds of ideas about illness were common at each developmental stage. Children of varying age groups were interviewed to assess their cognitive levels, and were asked about the causes, preventions, and treatments of illnesses. Kindergartners were found to define illness by external signs, and believed illnesses were caused by concrete actions that they did or did not do. Fourth and sixth graders defined illness by concrete symptoms, and attributed illness primarily to germs. Eighth graders defined illness as an abstract feeling of non-wellness, and understood that there are many causes of illness.

All of these studies support the idea that children's understanding of illness develops with their cognitive level. Younger children feel that they did something wrong to cause the illness, while older children understand that there are many reasons people become ill. Piaget's theoretical framework of cognitive development, as supported by empirical studies, provides one way of looking at ill children's experiences. In the case of adolescents living with cystic fibrosis, Piaget's framework supports the idea that such adolescents should be able to understand the genetic origin of their illness and that the illness is terminal. It is also plausible, then, that the adolescents should be able to understand how their treatments work and why they are necessary.

Although Piaget's theory explores the cognitive side of ill children's experiences, another aspect of those experiences that must be considered is the psychosocial one. Erikson's psychosocial stages provide insight into social and emotional development of

children. The stages that are most pertinent to adolescent development are industry versus inferiority, identity versus identity diffusion, and intimacy versus isolation. The industry versus inferiority stage occurs between 7-12 years of age and involves the child feeling that he is doing something worthwhile. This is often related to school and the skills that are developing there. The identity versus identity diffusion stage occurs between 12-18 years of age and involves the adolescent separating from family and uncovering a personal identity. The intimacy versus isolation stage occurs during the 20s and involves developing lasting intimate relationships with friends and partners (Thomas, 1996). These developmental issues are difficult for adolescents who are not ill and can become extremely overwhelming to the chronically ill adolescent.

Wolfish and McLean (1974) identify several areas in which the chronically ill adolescent differs from the "normal" teen: body image, school attendance and educational needs, sexuality, and life expectancy. Erikson's stages indicate that identity is a major issue at this age, and when body image, school attendance (and thus peer interactions), sexuality, and life expectancy differ from the norm the adolescent is left without support in developing that identity. One way for the adolescents to gain support, however, is through building relationships with other sick children. The sicknesses may provide a similarity, or common bond, from which friendships can be built. Wolfish and McLean (1974) say "The handicapped adolescent may find friendships only through a common bond of illness. Isolation from the normal course of teenage life may result in envy of healthy people, antisocial behavior, and sexual acting out" (p.1045). Bluebond-Langner (1974) points out similar concerns for terminally ill children.

In addition to the concerns revolving around identity, Bluebond-Langner (1974) and Richmond and Waisman (1955) discuss that terminally ill children also express concerns related to time and, more specifically, death. There is a fear of wasting time and a need to have things immediately. The issue of death is salient for these teens, although it

is generally not articulated. "Our suspicion is that this does not reflect an awareness but rather represents an attempt at repression psychologically of the anxiety concerning death" (Richmond & Waisman, 1955, p. 43). Mattsson (1972) backs up this suspicion by stating that children suffering from long-term physical illnesses employ denial and isolation as psychological defenses. Denial is particularly useful in the face of an uncertain future, as it allows these children to maintain hope.

There are many studies documenting the stress chronically ill children live with as well as their psychological adjustment to living with a chronic disease (Barton & Cattell, 1972; Lowit, 1973; Tavormina, Kastner, Slater & Watt, 1976; Bedell, Giordani, Amour, Tavormina & Boll, 1977; Isaacs & McElroy, 1980; Burns & Zweig, 1980). Tavormina, et al. (1976) interviewed and administered tests to 144 families with a chronically ill child. The participants responded to self-concept, personality, and locus of control measures. The results were that these children's scores approximated the "normal" children's scores, with several exceptions. "The cystic fibrotic youngsters were more dependent, less mature, and voiced more problems with intellectual and school status and their physical appearance (Tavormina, et al., 1976, p. 109). In addition, boys were found to have more problems than girls. Although these groups of children were found to have some problems, the results indicated that they were not the psychosocial deviants that stereotypes often imply.

Bedell, et al. (1977) administered psychological tests to 45 children, ages 6-15 years, to determine if life stress could predict the psychosocial functioning of chronically ill children. "The low life stress children had a more positive self-concept in general and rated themselves as being better behaved, more intelligent in school, more physically attractive, more socially popular, happier, and more satisfied with themselves than the high life stress children" (Bedell, et al., 1977, p. 240). Medical and environmental factors joined to create the psychological status of the children, suggesting that the

chronic illnesses of these children are not the sole determining factors of their psychosocial functioning.

Isaacs and McElroy (1980) describe some of the stressors particular to children with chronic illnesses. They cite fear of abandonment, misunderstanding of the etiology of illness, feeling different, disruptions in school attendance, changes in activities and educational goals, and reactions of peers as the most significant stressors for these children. All of the factors can contribute to a child's stress level and poor self-concept, as suggested by the Bedell, et al. (1977) study. These studies make it clear that in order to help chronically ill children adjust to their situations, an understanding of many social, emotional, and environmental factors needs to be reached. An understanding of individual experiences, and specific contexts for those experiences, would allow researchers to explore common aspects of the experiences of chronically ill children. This information would help caregivers to provide more sensitive and child-focused care to these children.

The studies concerning the psychosocial functioning of chronically ill children provide important information about the experiences of these children, and such studies are also available specifically concerning children with cystic fibrosis. Boyle, et al. (1976) performed a study indicating several areas of stress and concern for patients with cystic fibrosis. Twenty-seven adolescents and young adults were evaluated in a psychiatric interview and found to apparently function well on a daily basis. The areas of altered physical appearance, strained interpersonal relationships, conflicts in upbringing, and increased awareness of the future and death, however, were significant sources of emotional disturbances for this group. This group reflects the aging population with cystic fibrosis, and offers particular insight into the areas of concern for these older patients.

In addition, several other sources have pointed out areas of special concern for adolescents living with cystic fibrosis (Tropauer, Franz & Dilgard, 1970; Korsch, 1973; Galdston, 1973; Boyle, et al., 1973; Patterson, 1973; Dooley, 1973; Winder & Medalie,

1973; Burton, 1975; Waddell, 1983; Whyte, 1994; Harris, 1995). These sources provide information from case studies and interviews with patients, families of patients, and caregiving staff responsible for children who have cystic fibrosis. They point out that growth failure causes these teens to have poor body images. These adolescents experience continued dependence on their families and upon hospital staff which inhibits their independence. They fear rejection from their peers because of the symptoms of their disease and their differences from others. Finally, they are concerned about their futures. They wonder about their abilities to find mates, have children, and find employment that allows for their physical debilitations. Tropauer, et al. (1970) state "In the interviews, preoccupation with death and ultimate disability was seen frequently with adolescents. They also worried about the restrictions the disease imposed upon their social life and the lack of acceptance by peers" (p. 426). A final insightful comment comes from Galdston (1973) who says "The need to grow on schedule is of particular import to the child with cystic fibrosis who does not have time to fool around" (p. 383).

While these studies point out areas of concern for these patients, other studies have confirmed that cystic fibrosis patients can function at a similar psychosocial level to that of their "normal" peers. Drotar, Doershuk, Stern, Boat, Boyer & Matthews (1981) suggest that their "findings are consistent with a growing body of literature which suggests that children with cystic fibrosis can cope reasonably well with life tasks and that emotional disturbance is not an inevitable consequence of the disease" (p. 338). Similarly, Oke and Dewey (1997) found no differences in the social skills of children with cystic fibrosis and a normal comparison group.

All of the studies reviewed support the purpose of this project: to understand the experience of living with cystic fibrosis. The determination that a child's understanding of illness proceeds in a way that corresponds to cognitive development allows for the assumption that at different ages children will have different experiences of their illness.

Older children can be expected to have the most sophisticated understanding of their illness, and because older cystic fibrosis patients are a growing population their experiences need to be investigated. A more sophisticated understanding of illness for adolescents living with cystic fibrosis involves the recognition that the disease is terminal. These adolescents must learn to cope with the possibility of an early death and that may be extremely difficult. This, then, becomes an especially significant area of concern. The information about psychosocial adjustments suggests that although these children are capable of coping day-to-day, there are also issues that need to be explored to insure these children's well-being.

Another important issue is that while qualitative information has been collected from adolescents living with CF, most of that information has not uncovered the real meaning of being chronically ill for these adolescents. Davies and Addington (1973) state "We feel strongly that a patient's emotional life is directly related to his medical condition. However, we do not yet have adequate data to demonstrate what kind of a relationship this is or how one influences the other" (p. 68). Waddell (1983) says "Furthermore, by and large neglected in this debate on the worth of therapy for children growing up with cystic fibrosis, cancer, or muscular dystrophy are the thoughts of the recipients of the treatment" (p. 61). Also, Whyte (1994) suggests that phenomenological studies are necessary to provide in-depth information about the meaning of suffering and illness for children. A phenomenological study would be able to probe individual experiences. In order to understand why children with a chronic illness, such as cystic fibrosis, do have some psychosocial problems it will be important to find out exactly what the children experience in their daily lives and what meaning these experiences take on for them. In phenomenological terms, living with cystic fibrosis would be the ground against which other experiences are figural. In this study, many psychosocial themes emerged as areas of concern for these children. The potential exists for a greater understanding to be found

of what these fears/problems really mean to the children, of similarities that exist between children, and of what their needs are in terms of helping them cope with their disease. In order to better understand how the true meaning of the illness experience can be reached, it is important to understand phenomenology and its method of inquiry.

Phenomenological Perspective and Method

The research methods described in the articles reviewed were predominantly quantitative. Kvale (1983) says about quantitative research: "For the experimental method there thus exists generally accepted formal rules with respect to hypothesis testing, requirements of control groups, statistical methods with precise requirements for tests of significance, etc." (p. 172). These characteristics are typical of research that is guided by the scientific method. Information gained by quantitative research is factual, publicly verifiable, and generalizeable to a larger population.

Another type of research is qualitative. Qualitative research is often descriptive of people's actions and behaviors. Phenomenological research is qualitative, but focuses on a participant's experienced meanings. "The aim of phenomenologically informed research is to produce clear and accurate descriptions of a particular aspect of human experience" (Polkinghorne, 1989, p.44). In this type of research, the focus is on the participant's first person experience of the world. A participant's reality is individual and based on how that individual perceives the world. Although quantitative research focuses on experimental designs, qualitative phenomenological research uses participant observation and in-depth interviews to obtain descriptive data. "Qualitative research uses natural language descriptions (for example, unstructured interviews) for its data and usually presents the results in natural language" (Polkinghorne, 1989, p.45). This type of research can be seen to follow a three-step procedure, as presented by Polkinghorne (1989):

First, descriptions are gathered from people who have had the experience that is being studied. These descriptions are unanalyzed and are the truth as known by the participant.

Second, the researcher analyzes the data and begins to understand the common elements across descriptions. In this way the researcher can begin to describe the essence of the experience.

Third, a research report is written that accurately describes the experience being studied. The report should allow readers to gain an understanding of what the experience is like for someone.

In order to become involved in a research project that follows these steps, the researcher needs to shift from a positivistic perspective of research to a humanistic perspective. One such perspective is existential-phenomenology. Existentialism is concerned with human experience in concrete manifestations, while phenomenology is concerned with specific individual's experiences of existence. Existentialism and phenomenology want to produce "a rigorous description of human life as it is lived and reflected upon in all of its first-person concreteness, urgency, and ambiguity. For existential-phenomenology the world is to be lived and described, not explained" (Pollio, Henley & Thompson, 1997, pp.12-13).

One metaphor used to explain the existential-phenomenological perspective is that of figure/ground (Thompson, Locander & Pollio, 1989). The figure/ground metaphor suggests that human experiences may take on particular importance (i.e. become figural) and then later recede (i.e. become ground). A person's perspective and perception of the world is ever-changing, and so those experiential elements that are figural and ground are ever-changing as well. The meeting of person and world is the location of experience, and this is what existential-phenomenological research captures.

In the case of this study, having cystic fibrosis serves as the ground against which other experiences are figural. It is also possible for a shift in perception to occur causing the context of having cystic fibrosis to become figural against some other ground, such as Body, Time, Others, or World (Pollio, et al., 1997). Meaning is fluid and moves in both directions, so that a figural event may cause a new perception of context and vice versa.

One of the most frequently used means to collect data in phenomenological research is the in-depth interview. Taylor and Bogdan (1984) describe in-depth interviews as "face-to-face encounters between the researcher and informants directed toward understanding informants' perspectives on their lives, experiences, or situations expressed in their own words" (p.77). The personal interview requires that a relationship be established between the researcher and the participant, but before this can happen the researcher needs to become aware of his or her presuppositions regarding the research and the experience under investigation.

A researcher needs to ask himself or herself what attitudes, expectations, or biases he or she may have that could influence the interview process and data analysis. The researcher needs to "bracket," or identify and put aside, personal beliefs that may interfere with gaining a true understanding of others' experiences. "Bracketing is sometimes characterized as a suspension of theoretical beliefs, preconceptions, and presuppositions" (Pollio, et al., 1997, p.47). Another important function of bracketing is that it helps the researcher choose questions and prompts to use when talking with participants.

The phenomenological interview is concerned with individual experiences, but also with the meanings individuals attach to those experiences. "The face-to-face interaction of the interview allows the researcher to help the subject move toward nontheoretical descriptions that accurately reflect the experience" (Polkinghorne, 1989, p.47). The interview focuses on "what" questions rather than "why" questions in order to elicit experiential data.

Kvale (1983) presents twelve aspects of a mode of understanding of the qualitative interview:

First, the interview focuses on the life-world, or experiences, of the participant. The purpose is to describe the experiences of these individuals rather than the individuals themselves.

Second, the interview should elicit not only a participant's experiences but also the meaning of those experiences. The researcher needs to be aware not only of what is actually said, but what is said between the lines. An interviewer should be aware of nonverbal types of communication in addition to what is said. This dual awareness allows the researcher to formulate an understanding of what has been said, and he or she can then reflect the meaning back to the participant for confirmation or adjustment.

Third, the interview seeks to elicit qualitative responses rather than quantifiable data. The data will not be reduced to a number or set of statistics, but will be condensed into themes that provide an understanding of a specific experience. In this way, results retain individuality and variety as opposed to being converted almost entirely to statistical language.

Fourth, the researcher seeks to gain descriptions of experiences rather than broad theoretical statements. The researcher guides the participants toward detailed and meaningful descriptions of their life-world. It is also possible that the participants, as they talk, will find new meanings for themselves in their experiences.

Fifth, the researcher wants to describe specific situations or actions. The interview's purpose is to obtain individual data, not general opinions. The understanding of the essence of an experience requires that individual contexts be described in as much detail as possible.

Sixth, the interview seeks to obtain presuppositionless data. This implies that the researcher should be aware of his or her own biases and attitudes toward the research, and

that he or she should approach the interview without any ready-made categories for interpretation. In this way, the participants' ideas are more likely to fully emerge from the interview and the researcher is more likely to come to an accurate understanding of what an experience is like for others.

Seventh, the interview is focused on particular aspects of the participants' life-worlds. The interview is nondirective in the sense that the participant is responsible for which topics or issues will be discussed, but the researcher does guide the participant to speak of specific experiences rather than general theories or opinions.

Eighth, the participants may make statements that are ambiguous or that could have several interpretations. It is the responsibility of the researcher to be sensitive to such statements and to prompt the participants to clarify their responses. The researcher must also be aware of situations where the participants' responses reflect real inconsistencies or ambiguities in their thoughts about their experiences.

Ninth, it is possible that during the interview the participants may change their descriptions and understandings of their experiences. The discussion with the researcher may prompt further reflection on the experience, and so with each reflection the participant's understanding of his or her experience changes. Because of this it is impossible to exactly replicate an interview as can be done with quantitative studies.

Tenth, aside from the participants' changes, the interviews may differ based on the sensitivity of the interviewer. Interviewers will differ in their knowledge of the topic being investigated and in their interpersonal skills. Each interviewer will pick up on different nuances in information from participants and this may even be due to age, gender, or racial similarities or differences with the participants.

Eleventh, the interview is an interaction in which both the participant and the researcher influence each other by their reactions. The researcher needs to be aware of the dynamic of the interview while it is being conducted and during data analysis. As long

as the researcher recognizes the interaction, it serves as a strength of qualitative research rather than a source of error.

Twelfth, the interview may be a positive experience for the participant. The participant will be able to discuss a topic that is of interest to him or her with the researcher, who is also interested in that topic. It is possible participants will be appreciative of the interview experience because it felt valuable to them, and they may not want the interview to end.

Phenomenological interviews are semi-structured, meaning that the researcher has ideas about what topic or experience he or she wants to discuss but that the specific questions are guided by the participants' comments. Anyone who is familiar with the experience being investigated, and who is reasonably articulate, may be a participant. A researcher selects participants based on the variety they may provide to the data rather than on the need to fill a quota based on age or gender. The researcher can feel comfortable in terminating data collection when there is a repetition of significant phrases or ideas expressed across interviews, and no new significant information is being discovered.

It is possible that participants may view their experiences in distorted ways, and thus may report such distortions to the researcher. Researchers are responsible for verifying the reliability of the data they are collecting in the participants' self-reports. The potential exists for the researcher to be taken in by the participants' exaggerations or fabrications, but in phenomenological interviews it is more likely that the participants will report the truth (as they experience it) because they are equally as interested in being truly understood as the researcher is to truly understand their life-worlds.

Interpretation of interview data develops from the original question asked, and is an ongoing process. The goal is to provide an accurate description of a particular experience as it is lived by a particular individual. The researcher also desires to find

common elements of an experience so the essence of the experience can be described. For each interview, meaningful passages are identified which form thematic categories. Each passage is viewed in the context of the entire interview, and also in its relation to similar passages from other interviews. The structure of an experience develops from reflection on not only the pieces of the interviews, but their relationship to the "whole."

Neuman's Systems Model

As the structure of an experience must be described against the context of that experience, it is necessary to find a way to organize both the experiences and contexts so that they may be examined. In studying the experience of living with cystic fibrosis, Neuman's systems model provides a holistic organizational framework. This model is taken from nursing theory and was originally used as a tool for nursing students working in community mental health centers (Sohier, 1997).

Neuman's model considers the client as an open system. As such, the client receives input from outside (the internal and external environments), processes the input, and exports it as output. Although change is an integral part of the process, the goal of the system is equilibrium. Equilibrium equates with an optimal state of wellness, which is described as "the best possible state of health for a client system at any given point in time" (Neuman, 1995, p. 32). Disequilibrium, then, would be a state of illness. Neuman (1995) proposes that the healthier a client is, the better he or she will cope with stressful situations and the faster he or she will return to the optimal state of wellness.

Neuman presents the client system as a basic structure surrounded by various buffers, or lines of defense. Figure 1 presents a visual conceptualization of the client system. The client system is described as being continuously attacked by environmental stressors and the lines of defense protect the system from these stressors (Neuman, 1995; Sohier, 1997). The client's state of wellness impacts the effectiveness of the lines of

defense, meaning that when the client system is healthy the lines of defense are functioning at an optimal level.

The outermost level of protection is the flexible line of defense. Sohler (1997) says, "If the client takes appropriate health measures (e.g., eats a healthy diet, gets adequate rest), the client system can tolerate normal life stress and even extraordinary stress for a time" (p. 111). When the system is less healthy, however, the flexible line of defense becomes compromised and the next level of protection is affected.

The next innermost level of protection is called the normal line of defense. In the same manner as the flexible line of defense, the normal line of defense may be breached if the client does not engage in health-maintaining behaviors. If the normal line of defense is breached, the lines of resistance (life-protecting buffers) are open to attack and the basic

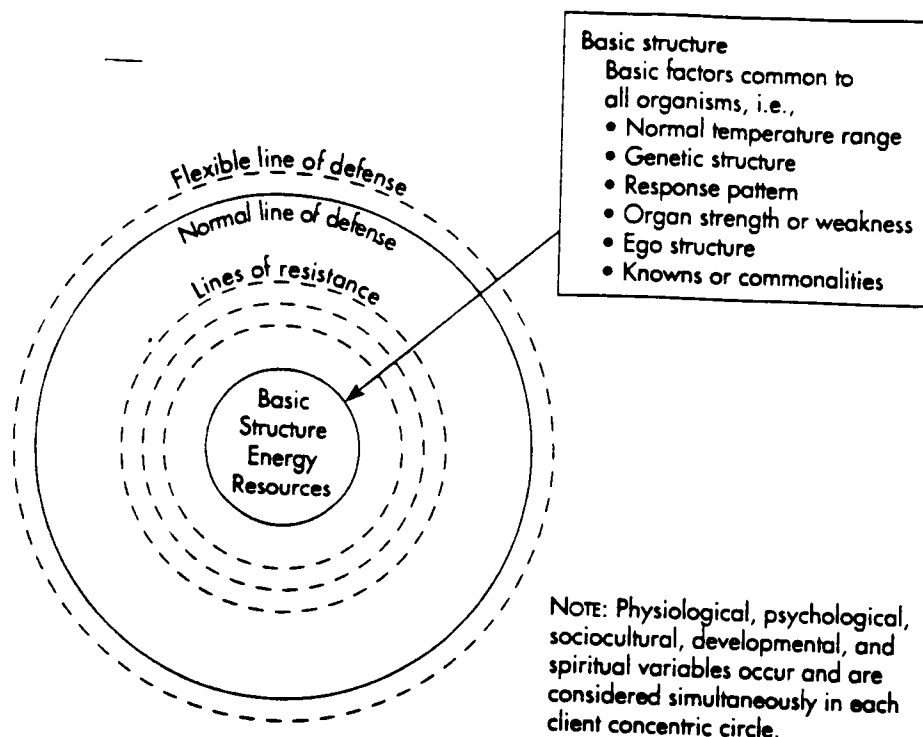


Figure 1: The client system. (From Neuman, B. [1995]. *The Neuman systems model* [3rd ed.]. Norwalk, CT: Appleton & Lange.)

structure and energy resources of the system could be compromised. This would constitute a life-threatening situation.

To use an example from Sohier (1997), as the flexible line of defense is breached a cold may develop. If the system remains uncared for, the normal line of defense becomes compromised and the cold becomes bronchitis. If, then, the lines of resistance are breached, the bronchitis may develop into pneumonia which could be life-threatening.

The stressors to the client system may be intrapersonal, interpersonal, or extrapersonal. Intrapersonal stressors come from the system's internal environment, such as a medical condition. Interpersonal stressors may reflect family problems, and extrapersonal stressors may be threats to a community. It is possible, and likely, that more than one type of stressor is affecting the client system at any given time. In order to describe the stressors of a client system, the system is assessed from five perspectives: physiological, psychological, developmental, sociocultural, and spiritual (Sohier, 1997).

In a seemingly phenomenological manner, clients are interviewed about their perspective on the problem that brings them to the caregiver. The results of this interview, or diagnosis, are reflected back to the client to see if the caregiver's objective determination matches the client's subjective determination of the problem. The caregiver then develops goals for client care by considering all of the system's stressors and asks the client to participate by deciding if the goals are appropriate and achievable given their specific circumstances. In this way, client strengths can be maximized and they can experience an internal locus of control concerning treating their illness. Considering the client's specific situation and abilities encourages compliance with treatment because it shifts control to the client and allows for individual circumstances.

Neuman (1995) identifies three types of caregiver interventions: primary, secondary, and tertiary preventions. Primary preventions take place when a threat to the system is identified but has not yet had an adverse effect. Secondary preventions occur

when a stressor has had an effect and something is done to insure that the system's basic structure will not become compromised. Tertiary preventions occur when the system is seriously compromised and actions are taken to restore the system to optimal wellness.

For adolescents living with cystic fibrosis the optimal state of wellness depends on the stage of their disease. An intrapersonal stressor, cystic fibrosis, is continuously attacking their lines of defense and this makes it easier for other stressors to take a serious toll on their defenses as well. The literature reviewed concerning chronic illness indicates that issues such as body image, fitting in with peers, and an uncertain future are all stressors that compromise defenses for the participants, in addition to the stress of simply being an adolescent. The adolescents in the current study discussed stressors that arose directly from the illness, such as physical symptoms or treatments, but also talked about other psychosocial issues. Each participant's individual experience was proposed to expose issues such as not being able to attend school, not being able to connect with other teens, or concern about the future and a possible cure. Neuman's model allowed all of the stressors that affect the participants, not merely the illness, to be considered so that the real meaning of being an adolescent living with cystic fibrosis could be described. This model allowed the adolescents to be viewed in terms of their optimal state of wellness rather than in terms of absolute wellness or illness. It permitted each person's circumstances to be evaluated individually, which is similar to the phenomenological method of inquiry, and involves the individual in developing a plan for his or her own care. Although interventions were not the focus of this study, Neuman's concepts of "preventions" and involving the patient in the care plan became useful in light of potential problems the adolescents discussed about their treatments. Neuman's model allowed each participant's stressors and coping mechanisms (lines of defense) to be evaluated, and when all of the evaluations were viewed together they provided an overarching understanding of the illness experience for adolescents living with cystic fibrosis. Now that the frameworks

for understanding the data have been discussed, the method and results of this study will be presented.

CHAPTER III

METHOD

Selection and Description of Participants

There are approximately 35 adolescents being treated for cystic fibrosis at the East Tennessee Children's Hospital (ETCH) and the ETCH cystic fibrosis clinic. Most are seen regularly at the clinic but there are others admitted as patients to the hospital who are not seen at clinic. All of these adolescents were recruited to participate in interviews for this study. No incentives or remuneration were offered to the participants. The selection criteria were that the children be between the ages of 11 and 19 years, that they be diagnosed with cystic fibrosis, and that they were treated at either the clinic or as a patient at East Tennessee Children's Hospital.

Those adolescents who were treated at the ETCH cystic fibrosis clinic were initially contacted by mail. They received a letter from the Child Life Specialist in the clinic and an additional letter from the researcher to introduce the researcher and the project. They also received a copy of a Parental Informed Consent for Adolescent Interview and an Adolescent's Informed Consent for Interview. Please see the Appendix for copies of both letters and informed consents. A stamped and addressed postcard was included in the mailing for the potential participants to respond to the researcher, indicating whether or not they would be interested in participating and a way to contact them. Please see the Appendix for a copy of the postcard.

Those potential participants that were recruited from the hospital while receiving inpatient care were identified through the researcher's contact with the patient census in her role as a Child Life Student at East Tennessee Children's Hospital. The researcher introduced herself and briefly introduced the project and gave the families copies of the letters and informed consents that were mailed to the recruits from the clinic. These

families also received a postcard to reply to the researcher indicating their interest in participating.

Participants in the study included four females and two males. Those who participated exhibited maturity and the ability to cope effectively with their circumstances, and it is possible that these were distinguishing characteristics of this group. Three were initially contacted by mail, and three were approached about participation while they were hospitalized. Of those contacted by mail, one was known to the researcher prior to initial contact about the study. Of those contacted in the hospital, two were known to the researcher prior to the study. One potential participant was angry at having received the initial contact letter as she considered it a breach of her privacy and she chose not to participate. The researcher was informed of the girl's concern by the Child Life Specialist in the clinic after the girl had spoken with her. All but one of the participants made the decision to speak to the researcher on their own behalves, with one participant indicating that although he was willing to be interviewed the decision was really made by his parents.

The participants were 11, 12, 12, 13, 15 and 16 years of age respectively. Four participants were diagnosed with cystic fibrosis within six months of birth, although one was not diagnosed until 5 years of age and another not until 8 years of age. All of the participants had siblings, however only one had a sibling who also had cystic fibrosis. That sibling is now deceased.

All of the participants were Caucasian. Three lived in suburban areas and the others lived in rural areas. All but one of the participants attended school regularly, with the exception of hospitalization and recovery times. One participant was homebound. A teacher came to her home to instruct her, although she did indicate that the teacher did not necessarily encourage her to keep up with school work because of the advanced stage of her illness. Three of the participants indicated that they were involved in several

extracurricular activities, usually sports, while the other three indicated no participation in extracurricular activities.

Three of the participants indicated that they maintained a high level of functioning and three reported that they experienced serious health problems on a regular basis. One participant said that he had never been hospitalized, although all other participants reported that they had been hospitalized several times each. The three participants who claimed a high level of functioning also expressed a high level of compliance with treatments, while those who were frequently seriously ill reported a lower level of treatment compliance.

Methods Used in This Research

Prior to any interviews taking place, the researcher participated in a bracketing interview. The interview was transcribed and subsequently analyzed by a qualitative research group. The interview provided the researcher with insight regarding her attitudes and biases about such topics as physician-patient relationships, parent-patient relationships, illness, and death. This information was used during participant interviews and data analysis to insure that the researcher's personal biases did not unduly influence either process.

After receiving postcards indicating an interest in the study, the researcher contacted the families to schedule a personal interview with the adolescents. The time and location of the interviews were mutually agreed upon by the interviewer, participant, and parents/guardians. All interviews took place in the participants' homes. The interviews did not take place at East Tennessee Children's Hospital or in any other medical setting. Parents and adolescents had the opportunity to have any questions they may have had answered, and then they were asked to sign and date the consent forms.

Before beginning the interview, participants were asked to fill out a questionnaire requesting demographic information. Please see the Demographics Questionnaire in the

Appendix. This questionnaire provided descriptive information about the participants, and provided information for possible probes during the interviews. The interviews lasted 30 minutes to one hour and were conducted using open-ended questions. Parents/guardians were not present during the interviews. With the participants' permission, the interviews were tape-recorded. The primary interview question was: When are some times that you are aware of having cystic fibrosis? Probes were added as deemed necessary, and most probes included a repetition or a paraphrased version of the participant's response. The participant was reminded at the beginning of the interview that he or she had the option to have any portion of the tape erased after responding to the interviewer's questions.

Methods Used for Data Analysis

Data analysis began with the first interview and was an ongoing process. Each interview was transcribed word for word. The transcriptions were subject to thematic analysis, which revealed categories of life experiences as presented by the participants. Reflection on previous interview data allowed the researcher to be aware of themes that arose in subsequent interviews and to connect common experiences that emerged across several data sets. Several interview transcriptions, with all identifying materials removed, were subject to analysis by two independent phenomenological research group to insure that the themes were arising strictly from the data presented by the participants at the first level of analysis. In these cases the transcripts were read aloud to the group and the group members offered ideas about the themes emerging from the data. All group members signed a confidentiality statement before hearing the transcripts. At a second level of analysis an overall thematic structure was derived from the data, and presented to the same group to confirm that all the themes were accounted for and to confirm the thematic structure presented in Figure 2. The following section presents the thematic structure as derived from the interview data.

CHAPTER IV

RESULTS

Thematic Structure

Data analysis revealed that the thematic structure involved three themes becoming figural against three grounds. Figure 2 provides a visual representation of the overall structure. The three major grounds are Body, Time, and Others. The three themes are Similarities/Differences, Doing/Stopping, and Support. All three themes cross the grounds of Body and Others, but only Similarities/Differences and Doing/Stopping cross the ground of Time. The themes are discussed as they relate to each of the grounds respectively, and brief overviews of the nature of the grounds themselves are provided.

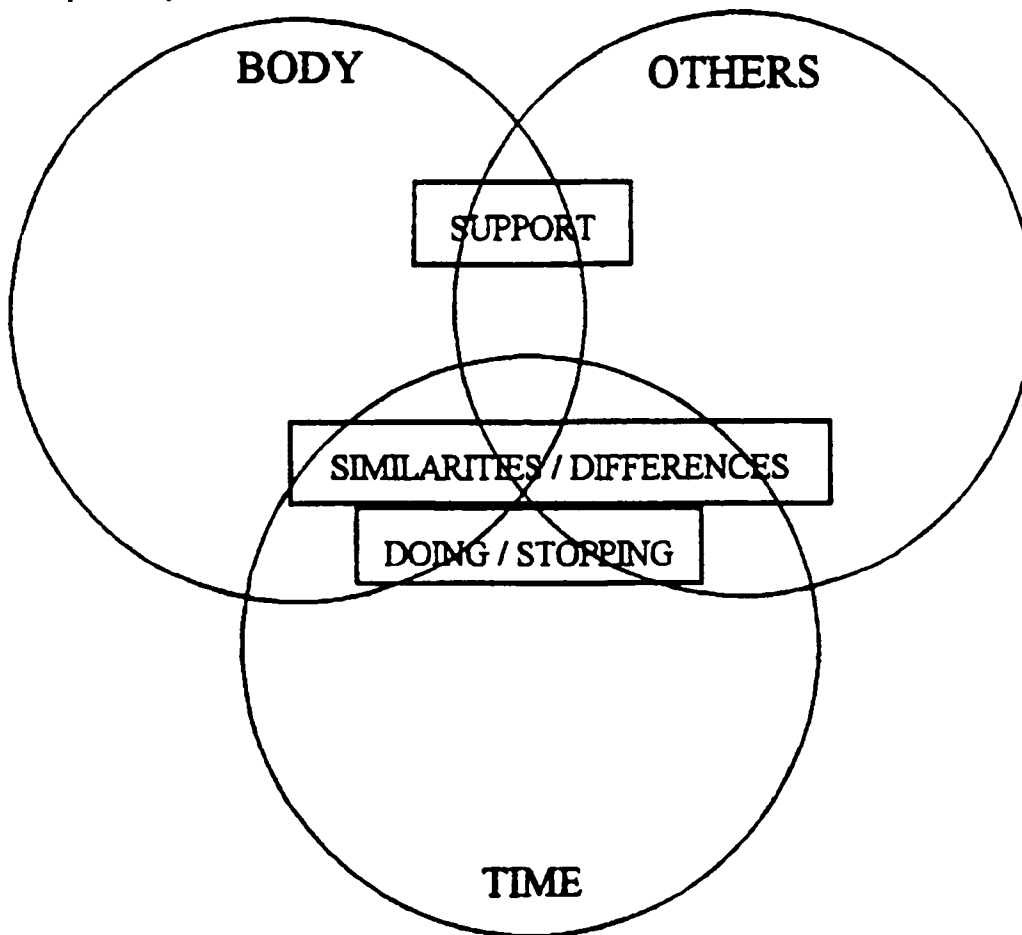


Figure 2: Overview of Thematic Structure

Three Themes Examined Against the Ground of Body

Body is the first ground that will be examined. The themes Similarities/Differences, Doing/Stopping, and Support all become figural against this ground. The first theme, Similarities/Differences, is concerned with the adolescent's desire to be the same as his or her peers and the significant differences that are experienced because of the illness. The physical symptoms of the disease along with the many medications and treatments that are needed to deal with those symptoms can leave the adolescent feeling different and wanting to be accepted as a person rather than as a person with an illness. These adolescents attempt to distance themselves from their bodies, and thus their illness, in order to be the "same" as their peers.

The second theme is concerned with the idea of "doing" something or, more specifically, being able or not being able to do something. When the body is perceived to be "healthy," the participants talk about the many activities they are involved in such as running, swimming, riding bicycles and playing other sports. When the body is perceived to be "unhealthy," the participants talk about the body as a restriction to activity. They must "stop" and not do the things they would like to do. The symptoms of the disease are manifested through the body so being out of breath, coughing and pain are all signs for the participants that they are "getting sick."

The third theme, Support, is concerned with the treatment of the disease. The many tests, treatments, therapies, and medications are all perceived as things done to the body that, while therapeutic, are often uncomfortable and unpleasant. Despite the unpleasantness of the therapies, however, the participants return repeatedly to the idea that these treatments support them by keeping the body "healthy."

Body as a Ground

Pollio, Henley and Thompson (1997) discuss a study in which participants were asked when they were aware of their bodies and what they were aware of in those

situations. The themes that emerged were Experiences of Engagement, Experiences of Corporeality, and Experiences of Interpersonal Meaning. The first dealt with the body as vital and active. The second dealt with the body as an instrument and as an object, and the third dealt with the body as appearance and as expression of self. These findings provide a framework through which to view the findings of the current study because the current data illustrate that the body is viewed in terms of activity, as an object, and also as an expression of self.

The participants discuss their identities in ways that closely associate them with their bodies. As will be discussed further, the participants view their bodies both as "self" and as "object." Pollio, et al. (1997) say that Gestalt psychology "implies that there is no stable body image, no static body representation independent of its present lived context" (p. 66). The context for the participants is that of being an adolescent living with cystic fibrosis. They both have bodies (the "selves"), and are bodies (the "objects" which suffer physical discomforts). Pollio, et al. (1997) go on to say, "In everyday life, the unity of the instrumental aspect of the body (being a body) and its experienced character (having a body) proceeds with little interruption" (p.68). A closer examination of the themes reveals that this is not necessarily the case for adolescents living with cystic fibrosis. These teens are intimately connected to their bodies because of the physical symptoms of their illness, but want their true "selves," or personalities, to be separate from the illness.

Similarities/Differences Against the Ground of Body

The theme Similarities/Differences deals with comparisons the participants make between themselves and others. They compare their bodies to those of their peers and find that symptoms of the disease cause their bodies to be different. Developmentally, adolescents are at a point where they strive to be like their peers, but this is particularly difficult for the participants because of their illness. As will be discussed further, the symptoms and treatments of cystic fibrosis restrict activity for the participants and this

makes them feel different from their peers. These differences are often downplayed in the interviews. One participant says, "Uh, sometimes in the middle of class if I like start coughing I just get up and walk out. Uh, it's pretty much normal." Another participant talks about coughing and says, "Uhm, no one ever notices it. They think it's just a regular cough." Another participant goes so far as to say, "I don't have any problems with the disease or anything." It appears that these adolescents would like to minimize the differences of their bodies in order to be more like their peers.

Although the participants minimize their physical symptoms, they also acknowledge their differences by explaining them to others. One participant states:

I tell them what cystic fibrosis is and how it affects the lungs and the pancreas, but what I'm trying to tell them is that on the lungs, my mucous is more thick and stuff inside than theirs.

Another participant says, "Uh, I just tell them that I have a lung disease called cystic fibrosis." Another statement concerns the use of the therapy vest: "And, uhm, we just told them how it helps you know with the lung and the functioning and how mine's different from theirs." All of these statements are made very matter-of-factly, with little elaboration, which is another attempt to minimize the differences between the participants and their peers. In addition, they refer to "the lungs" rather than "my lungs" in an effort to distance themselves from the bodily representation of the illness. They want to be accepted for their "selves" rather than their bodies' deteriorations.

Doing/Stopping Against the Ground of Body

The theme of Doing/Stopping is clearly articulated by the participants and serves to illustrate other ways in which the participants are different from their peers. Doing/Stopping refers to the ways in which the "healthy" body is permissive of activity and the ways in which the unhealthy body can restrict activity. This theme involves the idea of body as activity. One participant states:

And which, you know, I've been staying really healthy from playing basketball and stuff, and just going out in the subdivision and uhm I really don't have a problem with mine....Uhm, normally I play basketball uhm, in gym we'll play football or whiffle ball or something. Just run around the football field or whatever, have races, and uhm play volleyball and kickball and uhm sometimes we'll just go outside and we'll play tag and just different stuff. And uhm in the subdivision we play football like for two hours and uh jump on the trampoline and just stuff like that I think will also help me but is also fun. Not just for the cause but just fun.

Another says something similar when asked to discuss what he does with his friends:

Uhm, well we do regular stuff like we, my friend Bob, we like to bike a lot so we do that. Uhm, and we like to play basketball a lot so we play catch and play basketball and play Nintendo 64....Well, I do a lot of stuff like running and ride my bike and playing basketball. So a lot of exercise.

A third participant states, "When I'm not sick I'm at home or I'm playing, going to church, stuff like that. But when I'm in the hospital I can't do all those things and it's not very fun, and I hate being sick."

Staying active is clearly related to social interactions, but it is also connected to staying healthy. When the body is healthy more activities and more social interactions can take place. This illustrates one way that the themes as presented against the ground of Body are connected with the themes as presented against the ground of Others. One further statement clarifies the relationship between activity and physical discomforts:

"When I go jogging, swimming, sometimes I lose my breath and start to cough. Whenever I do different activities at school, like certain kinds of sports, it's hard for me to breathe so active things I can't do really well, but like simple things I can do really well." In this case the body is restricted from activity because of physical discomforts associated with the disease.

Related to the theme of Doing/Stopping, the body can also be viewed as an object. "The body can be experienced as having limits just as an ordinary object has limits. It can

become impaired through illness or injury. It reacts to events, is intruded upon, and intrudes into awareness" (Pollio, et al., 1997, p.79). As the illness causes deterioration in the body, the body is experienced as a restriction. When treatments are necessary, the body is experienced as having been intruded upon.

Continuing with the idea of the body as a restriction, one participant states:

Uh, when we go in the mountains the altitude makes it harder to breathe, and I have to go up stairs slow. Uhm, I just get out of breath if I like have to hurry around....Uhm, if I start to laugh really hard I'll usually start coughing. Uhm, if I swim I'll like get out of breath if I swim real fast or swim under water for a long time. Uhm, a lot of times when I wake up in the morning I'll be kinda congested just from laying down.

Another participant says, "I start coughing and getting very weak and can't go out and play or nothing....I can't breath and I have to wear oxygen and so that's how I know I'm getting sick." In a similar statement, another participant says, "'Cause I get real weak. Which that's how CF patients get, they get so weak that they don't feel like doin' nothin'." One final comment on this subject compares a person living with cystic fibrosis with a healthy person: "Well, they can run and play and do other things but they don't have to stop usually. They can just go on and do whatever. And then a person with CF has to stop because they start coughing real bad and then they're gasping for air."

The last several statements illustrate how the body's deterioration impedes activity for these adolescents, but they also reveal how the participants disassociate their "selves" from their bodies by distancing themselves from the illness. As discussed under the theme of Similarities/Differences, the symptoms are generalized to "people with CF" rather than personalized just as previously bodily organs were referred to as "the lungs" rather than "my lungs." This will be examined further during the discussion of coping mechanisms.

Support Against the Ground of Body

The final theme, Support, deals with the treatments of the body that maintain "health" and the recognition that this type of support is also tedious and intrusive. The

treatments support the body by allowing it to function as normally as possible (e.g., breathe more easily, digest foods more easily). One participant relates the following about her treatments:

But most of the time I don't have a problem with doing it. I mean, as long as it's something that's going to keep me healthy and uhm not in the hospital, that's the only thing I really care about.

Another participant discusses a time when he was hospitalized and the effect that had on him concerning his therapy:

I guess it kinda made me realize that it was more serious than I thought. Uhm, before I started to like not do my treatments as much and then like now I do 'em whenever I can.

A third participant says that she does not like her treatments, "But you gotta have it sometimes. Gotta deal with it." One participant even performed all of her treatments during the interview and explained how each treatment and medication helped her. A final comment sums up the true nature of the support offered by therapy: "I'll be able to breathe much better. Like close to a normal kid."

The intrusion of treatment, however, is also articulated very clearly by these adolescents. The intrusiveness of the treatments and the restriction they pose to activities can work against the support that they provide the body. Although the physical body is supported by therapy, it can have the opposite effect in a socio-emotional context by restricting social activity and marking the adolescent as different. Several participants describe these intrusions as "being bothered." One says, "I don't like surgery and I don't like feeling very bad. And I don't like when the nurses come in and poke around on me and stuff. When you just don't feel good you just don't feel like being bothered." Another discusses IVs by saying, "Uh, well at first they sorta like stick it in and stuff, when they're finding that vein and stuff, like when I was put in there (the hospital) in the summer they couldn't find the vein because it kept moving but uhm I don't usually like when they have

to take it out and fix it again." Similarly, a second participant says, "They, they couldn't get no IV in my arms or nothing so they had to shave me bald-headed 'cause I had a head full of hair, and put in an IV. So it ain't grown my hair back. It's just a big white spot." One final frustration: "Uhm, the biggest problem that I think I have mainly with it is uh, basically if like I have to take a certain pill that's like a big one to swallow."

The experience of body for these adolescents involves restriction and intrusion, as well as support, and this is occurring at a time in their development when they are seeking freedom and autonomy. The body can be viewed as an instrument that fails to support them in their search, and as it does not enable them to grow and develop in the same manner as their peers they attempt to distance themselves from it. These adolescents are seeking to establish an identity that centers around a "self" rather than around a body, however, they are often unable to engage in energetic activities with their peers because their bodies manifest symptoms of the disease such as shortness of breath and coughing. Boyle, et al. (1973) state:

Another factor contributing to emotional stress in older patients is the abnormal physical development seen in so many. Whether it was due to the delayed sexual maturation and retarded growth seen in adolescents or to the emaciation, large chests and chronic cough so prominent in patients over age 20, all the patients expressed anxiety and dissatisfaction with their bodies" (p. 386).

In addition to general dissatisfaction with their bodies, these teens are afforded little privacy. They are intruded upon not only in the hospital but in their homes, as well, when treatments and medications are necessary. Korsch (1973) states:

In the normal course of development, adolescence encompasses the time when the young person increasingly takes responsibility for himself and achieves independence from his parents and other adults in the environment. Needless to say, the enforced dependency inherent in major physical illness, the inactivity and increased dependency that is an integral part of every hospitalization or period of exacerbated chronic illness and the close medical

supervision that is required for these young patients curb the expressions of growing independence in almost all situations" (p. 373).

The developmental aspects of dealing with the body will be discussed more fully in a later section.

The themes as related to the ground of Body provide the base for understanding the experiences of these adolescents, and the themes as related to Time and Others are intimately connected to them. These adolescents find that their primary mode of existence revolves around the need to care for their bodies and the desire to integrate that care into some sort of viable human experience.

Two Themes Examined Against the Ground of Time

The themes Similarities/Differences and Doing/Stopping will continue to be examined against the ground of Time. As before, Similarities/Differences is concerned with the comparisons these adolescents make between themselves and others. They must take time for treatments, take time to be hospitalized if necessary, and overall have a shorter amount of time to live than their peers. Related to Doing/Stopping, these adolescents must stop what they are doing for treatments and medication during the course of their daily schedule, and feel as if they are moving at a different pace from their peers.

Time as a Ground

Time is generally thought of as something that can be broken down into homogenous units. Chapman (1997) points out, "Human or lived time is neither so fixed nor so regular and is better described as 'flowing' in an episodic and inhomogenous way. Human time, what Bergson called *duration*, is lively and irregular and experientially distinct from metric time" (in Pollio, et al., p. 100). Perceiving time in this manner makes it more personal, and it is the personal experiences of time that the participants relate in the interviews.

In order to understand the meaning of time in a situation, such as living with cystic fibrosis, it is necessary to determine what people consider to be figural about time itself. Chapman (1997) presents research in which 20 participants were asked to talk about their experiences of time. Four themes emerged: Change/Continuity, Limits/Choices, Now/Never, and Fast/Slow. The first theme, Change/Continuity, "concerns an awareness of personal development or of our 'becoming' in time" (Chapman, 1997, in Pollio, et al., pp. 105-106). Limits/Choices concerns the choices people make and limits they accept in order to be able to do the things they want to do. The theme of Now/Never deals with people obtaining the things they want and the urgency they feel about doing so. Finally, Fast/Slow concerns the tempo of life; whether it is moving quickly or slowly (Chapman, in Pollio, et al., 1997).

In some way, all of these themes are reflected in the discussion of time in the current study. Change/Continuity deals with development, and developmental issues are certainly important for these adolescents. The other three themes are reflected as well in the participants' discussions of the choice to take treatments but limit their activities, the realization that they have limited time to live and the urgent need that creates to "live" and to fit in, and the realization that they are living at a different pace from their peers.

Similarities/Differences Against the Ground of Time

Similarities/Differences as a theme concerning time deals with the comparisons the participants make between how they spend time and how their peers spend time, and also concerns the comparison of how much time to live the participants and their peers have. Treatments and hospitalizations interrupt activities and social interactions, and serve to further isolate these teens from their peers. The use of minimization becomes a useful tool again, as one participant discusses her illness: "Uhm, I just try to make them see that I'm not different. It's just that I have to do something more that will take a little more of my time." Another participant discusses how all of her treatments make her feel: "It kinda

makes me mad 'cause I can't do like normal stuff that other kids can." These adolescents must take time for treatments in order to maintain "health," but that necessity differentiates them from others. One participant says the following when discussing how her friends perceive her treatments: "And you know she's a normal, you know, and she don't have it and everything." She is pointing out that her healthy peers do not understand the necessity of taking time for treatments. These adolescents, while desiring to be the same as their peers, understand that the daily schedule of their lives makes them different.

The most significant difference between these teens and their peers is that they have a considerably shorter life expectancy. "As one matures, the focus shifts from having 'things' in time to an experience of 'having' time itself. The balance shifts from childhood to adulthood in the amount of time we *have* left, from 'more of it is ahead of us' to 'more of it is behind us,' so that the time remaining becomes increasingly valuable" (Chapman, 1997, in Pollio, et al., p. 109). For adolescents living with CF, this shift begins to occur as soon as they begin to understand what it means to have a terminal illness. Piaget's cognitive theory proposes that by the teenage years, these children can truly understand that they are going to die.

The concept of an uncertain future is expressed more in terms of what the participants did not say rather than what they did say. The idea of death and a shortened life span was generally avoided with specific reference to how long each participant would live, unless it was to state how each person had far outlived any projected time-frames given by doctors shortly after birth. They frequently referred to themselves as "miracle children." This distinction, while positive, is yet another sign that they are different from their peers. In addition, issues such as the deaths of relatives, the idea of a cure, and unkind comments about death made by peers were discussed in a way that implied that the participants understood that they had limited time to live, although they would not say that specifically.

One participant relates an experience she had with peers at school:

And most of the time, I've had trouble with these girls that I don't really like at school you know, saying I'm not going to live before I'm 18, you know that's something that I'm not worried about because uhm, she, she the girl that has talked about and said this behind my back, uhm we've had people talk to her because she really don't like me so I think that was why she was saying it and uhm, you know my friends have been there and we've told her some stuff you know. Uh, we just say you know, you don't know nothing about it; you don't need to be saying it and uhm it happened one time this year and it's quit after that. And it's just something that don't bother me at all because I know the good and not the bad about it.

She, as in earlier cases, distances herself from the disease by addressing the issue of the girl who does not like her rather than the possibility that what the girl has said is true.

Another participant uses a similar distancing technique when discussing the death of a cousin, who also had CF, following a lung transplant:

Uhm, well she got her transplant in May. The transplant went good, but she got like an infection and she died. Uhm, she was 18. She lived in Texas. I didn't get to see her that much....Uhm, kind of scared about getting my transplant but I mean I've got to get one so I might as well not be too worried about it. Uhm, just kinda made me think you know like she's 18, I'm 16. So...

He implies that he has made the connection that he is close in age to his cousin, and that the same thing could happen to him, but he never makes a direct statement that he is afraid he will die. In this way he acknowledges a similarity between himself and his cousin, but maintains hope for a different outcome. Yet, he indicates some vague fear of the transplant. Another participant discusses a fear of surgeries, and a fear of not waking up, but never directly speaks of death:

Well, I don't like having surgeries. That's scary. And I don't like that experience because when you go into surgery you're like is it over yet? And stuff like that. And you don't think about going to sleep, you think about waking up. Like am I going to wake up? And you're not thinking

about is this gonna hurt or something like that. You're thinking about am I gonna wake up, am I gonna wake up, am I gonna be in ICU, or will I have a ventilator and stuff like that. But when you wake up it's all over and you don't have to worry about it no more....And sometimes it's scary not knowing what's gonna be.

The final phrase sums up the fact that these adolescents have an uncertain future, an unknown amount of time left, and that makes them significantly different from their peers. This participant discusses her life expectancy, and always phrases it in terms of life rather than death. She says:

And they used to tell me a long time ago when I was born, they told my mom and my family and stuff that I wouldn't live to be a year old. And I'm 12 now, and so everyone says I'm a miracle baby. I like that.... 'Cause my motto is that when it's time to go it's time to go, and there ain't nothing you can do about it. But that doctors or anybody in this world can't tell you when you're gonna go. The only person that knows that is God. And that's it. They can't go, 'Well, you're gonna live six months' or 'You're gonna live just one year' or 'You're not gonna live to Christmas.

The same participant, however, indicates that she is aware of an impending death when she discusses the death of a grandmother. The grandmother died of emphysema, a lung disease, and it is clear that this resonates with the participant. She states:

Very upset. Very scared. 'Cause she was like my mom to me. She, a long time ago when she wasn't that sick, we used to get out and drive around. Me and my papaw and my mamaw. We'd go shopping and stuff. That was a lot of fun. And so, when she passed away and got real sick and stuff we couldn't do that and I felt bad. And it was scary and.... It made me feel bad, upset. Because it was...she would get to the point where she couldn't breathe at all and so it was scary. And when she got real sick, a couple days before she passed away, that scared me half to death because I knew something was going to go wrong. So she had to be on a ventilator and stuff like that and I didn't like it and it was scary. It made me very very upset. Made me feel bad myself.

She indicates that she relates to the grandmother's final illness and death by her observation that a ventilator (artificial breathing device) was used and her statements that

it made her "very very upset," but still does not directly discuss death in relation to herself. The participants imply a subtle acceptance of their uncertain future but also show that to maintain hope they must maintain a distance from the reality of death. Galdston (1973) says such a distance "suberves the function of protecting a delusion which is central to the organization and application of the patient's energies in life, i.e., that he will live out his days to their natural fullness" (p. 379). This use of distance and disassociation from the illness is healthy in that it allows the adolescents to keep living with hope for the future. These defense mechanisms will be discussed further in a later section.

As already pointed out, a shortened life span, along with the need for time-consuming therapy, serves to isolate these teens from their peers and others. For these teens Time and Body are related because time must be taken to care for the body, and the weakness of the body will eventually end their time to live. Also, Time and Others are related in that the time spent caring for the body is time spent away from others rather than spent in peer interactions. Adolescence is a time when most teens are searching for independence and identity. They bond with peer groups and go to great lengths to fit in. For teens with CF, however, this is when the time needed for medical care keeps them dependent upon others and makes them not fit into a standard peer group. Their experience of time is one of frustration because they want to fit in just like everyone else, have to deal with time as something that often keeps them from fitting in, and understand that they have only a limited amount of time to fit in and experience life. Korsch (1973) says "Adolescents with chronic illness who may require repeated and extensive hospitalizations and who are generally forced into deviant daily routines and behaviors are often alienated from their natural age mates and pushed into increasing isolation, social deprivation, and loneliness" (p. 373).

Doing/Stopping Against the Ground of Time

The theme Doing/Stopping is closely related to the Similarities/Differences theme. The daily schedules for the participants are all about stopping activities to have treatments and being able to do things, but at a different pace from their peers. Chapman (1997) says "Since human existence is always in-the-world, Merleau-Ponty views the experiences of time in terms of the perception of time which, like all perceptions, is sensitive to change and continuity - *change* in which aspects are figural, *continuity* in which aspects relate to the situations of one's life" (in Pollio, et al., p. 118). Considering time from the perspective of the participants, it becomes apparent that their perception is that their treatments take time away from doing other things. Also, as stated above, to stop doing means time away from friends. Their regimens of treatment constitute the continuous aspect of their perception of time. While discussing activities that she engages in with friends, one participant states "I want to do that but uhm I have to do my therapy. My mom will say, well you have to do your therapy first, and it takes about 30 minutes and sometimes I don't ever feel like doing it because I'm wanting to get out there so I can play longer." Another participant says something similar: "I guess I'm just used to it by now but it sometimes gets aggravating. When like you're at home and you're playing or doing something and your mom goes 'It's treatment time' and you're like 'No.'" All of the participants are very specific about how long their treatments take, as if they are documenting how much time they are losing for other things because of the disease. Another participant specifies not only times, but amounts of medicines for his treatments as well: "Uh, it's pretty annoying having to do it every day and night. I don't always do it. Uhm, it's not that bad. It takes about 15-20 minutes....I do 240 milliliters of tobrimycin every morning and every night and I do one vial of pulmozyme at night. And the pulmozyme takes about five minutes and the tobrimycin takes about 15." These statements make it clear that the time-consuming nature of the treatments are, at least

partly, responsible for adolescent non-compliance with treatment. The other side of the daily schedule, however, is that it was generally recognized that complaining only made treatment take longer. One participant says,

Uhm, usually when I'm doing my therapies watch TV or do my homework or play on computer. Since I can't really do anything else or go outside....Sometimes I'm frustrated and like whine and complain about it, but then that usually just takes up more time so I have to, that takes up more time so I can't do what I want to do and then sometimes when it's, when I have nothing else to do I just forget it and do it. But it usually takes me longer to do that because I'm like engrossed into the TV or something.

It is clear that these schedules, while maintaining health, are tedious. They cause the participants to have to stop doing things, to take time away from their friends and activities, and generally restrict all social interactions. These schedules restrict what the participants can do and perhaps make them more aware than their peers of the value of time. Chapman (1997) points out "Our experiences of 'doing in time' concern how we cope with what we experience as limited amounts of time. Time thus becomes a commodity, like money, either to be wasted or well spent" (in Pollio, et al., p.107). Even the hope of a cure is phrased in such a way that it would allow the participants more time for activities rather than extending their life span, per se. "Uhm...I think that'd be cool. My mom said something about you take a little pill instead of doing your therapies...your inhaled therapies I think. Yeah, and your flutters. So you don't have to do your therapies and I can just play. So I don't have to wake up at six in the morning every time and go to bed at 10." For the participants, the realization that they have very limited time means that each moment has to be lived to its fullest. As noted under the heading of Body, being able to "do," or participate in activities, is very important to these adolescents. For them, activities equate with life because being able to be active means that they are "healthy," and as long as they are "healthy" they still have time to live.

It is important to note, however, that being active and alive does not necessarily mean that the participants can "do" at the same pace as their peers. One participant speaks of his friends, "Sometimes my friends will get annoyed they have to wait sometimes....They just haggle me like 'Hurry up slowpoke!' Something like that." Another discusses the differing schedule of her day at school, "It aggravates me 'cause kids ask about it. 'Why do you go to the nurse all the time? Why do you have to stay there almost half the day?'" Another discusses his activity level when friends are over. "Sometimes they want to go outside though and play, and I just let them go outside and I do something and then I go outside." Even when the participants are involved in "normal" activities such as school and play, they must often slow down to keep from having to stop altogether. They are moving at a different speed than their peers, and this differentiates them as well. It is clear that the two themes examined against the ground of Time are closely related, as the things that make the adolescents the same or different from their peers are the things that allow them to "do" or make them "stop." The themes will now be examined against the ground of Others to determine how these adolescents interact with their peers, caregivers, and others with whom they come in contact.

Three Themes Examined Against the Ground of Others

"Along with the major grounds of time and body, a phenomenology of the other is necessary to contextualize any attempt at describing human experience" (Pollio, et al., 1997, p.125). Relationships with others, particularly peers, are very important to the participants. They see the ways they are the same or different from their healthy peers. They also connect with other sick children because sickness provides a common bond on which to build friendships. Their treatments interrupt interactions with others and since parents are often the ones to interrupt by indicating that treatments are needed they are seen as "nagging." Finally, others provide support systems for the participants to help them cope with the disease and its repercussions.

Others as a Ground

One assumption taken from Gestalt theory is "that society as both an objective fact and a perceptual experience serves as a continuing ground for any and all experience" (Pollio, et al., 1997, p. 131). The objective fact is that when the participants compare themselves to their peers there are real differences between them. As a perceptual experience, however, these differences may be exaggerated or downplayed and this affects the participants' views of themselves and others.

Martin Buber presents the contrast of the I-It and I-Thou relationships. The I-It relationship means that "the person relates to everything in his or her world as an object that I can use or manipulate" (Pollio, et al., 1997, p. 139). The I-Thou relationship, however, means that the I considers others as human beings and makes a connection with them (Pollio, et al., 1997). The participants' desire to be "the same" as their peers indicates a desire to be related to by others in an I-Thou manner rather than an I-It manner. Being related to as a person is important to the participants in all their relationships with others, but especially with their peers. Their peers are most likely to notice their differences and possibly to avoid them because of those differences. This is difficult for the participants as adolescence is a time when they hope to identify with a peer group. This theme of Similarities/Differences will now be examined.

Similarities/Differences Against the Ground of Others

The theme Similarities/Differences is very prominent against the ground of Others. The participants find a way to indicate that they are really "the same" as their peers despite any differences they may have just discussed. One participant says of his experiences of living with cystic fibrosis, "Uhm, they're not really as bad as people think I guess. I mean I live a pretty normal life." Another participant discusses his experiences at school and says:

Uhm, well I'm in 6th grade and uh it's just like any other person at school, learning and, see I don't have to do anything, well I have to take pills at lunch. But they already know about that and I'm not embarrassed

or anything....Well, at school it's just like anyone else I said, and it doesn't bother me....Well, usually I'm just like any normal kid.

These statements, and others like them, were frequently made directly following a description of coughing spells or treatment times and they indicate that the participants feel the need to downplay any visible differences. One participant, however, does eventually admit to feeling different when discussing her treatments. She says:

Well, I just don't like to take it....Because it makes me feel like I'm weird or something. Like I'm different from everybody else. It made me feel bad. I mean I just usually stayed in my house most all the time.

While there are obvious differences between these adolescents and their peers, it is also important to recognize that there are ways in which they are "the same" as their healthy peers. The most prevalent area of being the same was in relation to parents. One participant says about his relationship with his father, "Uhm, I guess it's normal. He likes to boss me around, tell me to mow, take out the garbage, stuff like that." Another participant discusses her relationship with her mother:

Really I don't think anything is as hard for her, uhm, just trying to get me up and get me ready. Is basically all I think, and trying to get me out of the bathroom 'cause me getting my bangs done is one of the biggest problems we have.

These examples indicate that there are some typical teen behaviors that the participants do engage in. This is important to realize because aside from being chronically ill, these adolescents are still dealing with typical developmental issues such as appearance and rebellion against parents.

Another way that the participants can be viewed as "the same" is in relation to their peers who are also living with illnesses. One participant discusses being in the hospital: "I meet a lot of other kids and you know if they're having trouble and stuff I try to talk to them and understand what's going on with them and uhm try to be their friend

and help them whatever they're in there with." Another participant talks about meeting other who have cystic fibrosis: "Until I met people in the hospital that had CF I thought I was the only one that had it....It made me feel better because I knew that I was not the only one that had it." Another participant expresses a similar emotion: "Yeah, when I was up in Duke there was at least, I'd say, 5 or 6 of us up there with cystic fibrosis. And I got to understand how their lifestyle was and meet them....You know I felt better around them because they had the same thing and they know what it's like." This connection with other sick children is clearly important to the participants because it allows them to feel understood and not isolated. Although this "sameness" is unfortunate in that it involves poor health, it is profound in the connection it allows the participants to feel.

One final comment indicates that there may be some advantage to being different. One participant discusses a difference in maturity between himself and his peers:

Uhm, it's, I've learned to deal with stuff better than most of my friends I guess. Uhm, I don't really take things real serious that like I can't really help....Like if one of my friends that's perfectly healthy was thrown into my position they'd probably like freak out or something.

These adolescents exhibit maturity in many ways, and are aware that this makes them different from their peers. They show an amazing ability to be resilient in the face of a terminal illness, and to cope in productive ways.

Doing/Stopping Against the Ground of Others

Doing/Stopping as a theme in relation to others involves the way that having to limit activities influences the participants' interactions with other people. The physical symptoms of the illness often puts a stop to activities, as do treatments, and this can isolate the participants from their peers. Another aspect of this theme involves the role of the caregiver who can be seen as "nagging" when he or she indicates that treatment time is near or that the participants cannot engage in particular activities.

Concerning treatments, one participant says:

See while other kids are outside playing, and then I have to be called in to take my treatments. And then when I get back out everyone's done gone or going in and then I have to go in. And usually I can't do what they can do like run around a whole lot, ride bicycles a lot, just stuff like that.

Another participant tells a similar story when he discusses treatments: "It's kinda, like when I have friends over to spend the night and they're like 'Let's go to the mall' and I'm like 'Well c'mon. I've got to do this.'" Treatments maintain health but they disrupt social interactions. The participants are either made to choose whether or not to do their treatments as opposed to being with peers, or the choice is made for them by caregivers. Another participant discusses her feelings about having to have treatments rather than social time by saying that it makes her "Upset. Sometimes bored. Sometimes mad."

Aside from isolating the participants from their peers, treatments can also influence the relationships these adolescents have with their caregivers. Caregivers are often responsible for making sure the participants stay on schedule, but their vigilance is often considered "nagging." One participant discusses his parents nagging by saying, "Uhm, well, I know they're doing it for my own good, but I get sometimes sick and tired of it." Another aspect of limitations imposed by caregivers comes not when they limit activities with treatments, but when they limit activities that may exacerbate the symptoms of the illness. One participant discusses such a limitation as a time when he is aware of having cystic fibrosis:

Uhm, oh when my parents tell me like, uh well, for example, my friend was over, Bob, we found out that a professional dirt bike racer lived in our neighborhood. Mark, Mark uhm oh yeah, Mark Brown. He's like the 5th best in the country. He lives right down the street from us and uh, his wife said like maybe they'd get us some tickets. And my mom said like well, I don't know if that'd be the best place for you to go to a dirt bike race because there's a lot of dust.

In this example, not only does the caregiver impose limits but those limits will ultimately influence the participant's ability to interact with his peers.

The limits imposed by symptoms, treatments, and caregiver vigilance all influence the participants' relationships with their peers. This is a time when adolescents are seeking autonomy and identity, which is found through separating from parents and identifying with peers. The participants have fewer opportunities to interact with their friends, and when they do interact they are often unable to fully participate in the activities. The need to stop marks the participants as different, and this difference can be isolating. This isolation can, however, be countered by the support the participants receive from parents, friends, and other caregivers.

Support Against the Ground of Others

The theme of Support involves the ways that other people help the participants cope with their illness. This can take the form of helping with treatments, providing humor, paying bills, fund-raising, or simply being available for the participants. Support most often comes from people who are knowledgeable about the disease such as medical staff, relatives, or friends who have learned about the disease.

One participant considered support to be a global financial phenomenon. He discusses fund-raisers for the Cystic Fibrosis Foundation that his parents are involved in:

Well, we get a bunch of people like my classmates and people at my mom's work and a bunch of people come and walk around at the park....And they, they get uhm, like money to give to the CF Foundation.

He goes on to talk about the support his grandparents provide by saying, "Oh, well my grandparents are real supportive. They pay for all my insurance and all my medicines and stuff. So they're really supportive." The participant makes a final comment that reveals just how important this financial support is: "Well, money's probably important, most

important thing because you have to like, the scientists have to like buy all the medicines and the supplies so they can like figure out what to do." This type of support allows the participant to maintain hope for the future; hope that there might one day be a cure.

Another type of support comes from those who help with the medical aspects of the disease. One participant talks about her mother helping with treatments: "She fixes them for me and gets them ready and stuff. And she takes care of me. She's a good mom." The same participant goes on to talk about hospital staff and her doctor:

Like some doctors, they're doctors but you know how it is. They kinda don't know what they're doing. But this one does. And the nurses and stuff there, they know what they're doing. They know how to take care of me and stuff.

Another participant discusses friends' support by saying:

Karen, one of my other best friends, she, she's really helped me a lot, helping me keep up with my enzymes, making sure that I'm taking them. And you know, I have a lot of really good friends that try to help and try to do their best to help me, take my medicine and remember to and uhm do my therapy when I'm supposed to when I'm over at their house when my mom's not there.

A final comment captures the true importance of this type of support. This participant describes how it makes her feel that her mother is there for her:

A lot better because sometimes I can't do it all myself. She's always there when I'm sick, and makes me feel better....I know if I get sick or something momma will take over and do it [treatments] for me. She will encourage me on to do the stuff I need to do.

This type of support allows the participants to be independent in caring for themselves when they are able, but also allows them to be dependent if it is necessary. Their family, friends, and care-givers offer an assurance that the responsibilities of treatments do not have to be handled alone. They are available to encourage, remind, and even take over if necessary to help the participants remain as healthy as possible.

Another important component of support involves laughter and fun. This can be provided by friends, family, and even caregivers from the hospital. One participant talks about her family cheering her up:

I love being with my Papaw. He's fun, and he can make you laugh. Well, like when I'm up in the hospital and he comes to see me, and him and my older brother, they come and see me and cheer me up.... They make me laugh and stuff by telling jokes and acting funny. I like it. And being with my dad, well he's the same way. He can make you laugh too.

Another participant talks about how her friends help to keep things lighthearted:

They try to help me laugh like when I'm mad or something 'cause I have to do that [treatment] they'll try to cheer me up by saying 'Well, if you get it done we can you know stay out longer or go to the movie later' and they really help me a lot through that like at school and stuff.

Another participant talks about a trip she took with hospital staff to an amusement park:

"And when I get really excited on a ride I lose my breath. Because I laugh so hard it's just knocked out of me." This is one instance where being out of breath is a positive experience for the participant.

The humor and lightheartedness, whether on an everyday basis or during a special occasion, allow the participants to take a break from the tedium of their daily schedules of treatments and medications. It allows them to connect with their healthy peers in an uplifting way. This laughter can help these adolescents make it through one more treatment or one more hospitalization and can help them cope with the illness on a day-to-day basis.

DISCUSSION AND IMPLICATIONS

Phenomenology and the Human Experience

The purpose of phenomenology is to explore human experiences and the meanings those experiences hold for individuals. In broad terms, the participants in this study were found to be creating a human experience despite the adverse circumstance of living with a terminal disease. Living with cystic fibrosis was the ground against which all of their experiences became figural. They discussed their experiences of Body, Time, and Others in terms of similarities and differences, doing and stopping, and the support they received. Perhaps the most important aspect of this study is that these adolescents were permitted to discuss what their individual experiences of living with cystic fibrosis meant to them. Phenomenology provided the methodology by which the grounds of Body, Time, and Others emerged as a means for understanding the data. One way to help provide structure and meaning to the results is through Neuman's Systems Model that speaks to the role of stressors which incorporates growth and developmental issues related to being an adolescent. The three themes in the data highlight the areas of stress for the participants.

Role of Stressors

Neuman's model provides five variables, or areas of the client system, that may be affected by stressors: physiological, psychological, sociocultural, spiritual, and developmental. In addition, each client system has lines of defense that protect against stressors. The thematic structure presented above also reflects areas of stress and coping mechanisms. The participants gave some insight into both stressors and coping mechanisms and these will now be discussed.

Physiologically, the participants suffer from a disease that affects their ability to breathe, to digest food, and ultimately to grow. The participants discuss coughing, shortness of breath, mucous secretions, and inability to digest food in a variety of ways.

These physical symptoms make them obviously different from their peers, cause them to have to limit or stop activities, and cause them to seek support through treatment and medication. Aside from the obvious stress in terms of Body, this physiological stress also involves the grounds of Time and Others. The body's physiological deterioration makes the adolescents aware of their uncertain future and causes them to spend time away from others for treatments. The lines of defense, or support, offered here are also physical and grounded against Body. The physiological stressors, then, have far-reaching implications that affect more than just the physical body.

Psychologically, these adolescents experience many stressors. In the data there are many examples of how their differences separate them from their peers, and the adverse effect this may have on their sense of identity and well-being. They discuss how the need for treatment interrupts social interactions such as playing sports or going to movies, and the remarks made by peers about their deaths. They are faced with an uncertain future. There is the hope for a cure, but the reality is that many will die at an early age. Again, this stressor can be seen to run across all three grounds. Body is central, as it is the physical symptoms of the disease that are mainly responsible for the psychological distress. The fear of an uncertain future is grounded against Time and the many differences these teens live with shape their experience of Others. Another aspect to be considered is that it is in the ground of Others that the adolescents can find support, or defense against, the psychological stressors. Others who are knowledgeable and accepting form a support system for these teens.

From a sociocultural perspective, the adolescents are aware of the financial burdens of treating the illness. They must seek the support of the community to raise funds for research, and the support of extended family to find funds for daily treatments and insurance. The role of Others in providing defenses against this type of stressor is evident. Other concerns involve the effects of extended absences from school, and a lack

of acceptance from peers. Absences from school may cause the adolescent to become homebound, and the participants relate that this can be lonely and discouraging. The lack of acceptance from peers is also discouraging, and the participants talk about being most comfortable around other sick children or those who have knowledge about cystic fibrosis because they feel better understood with these people. It is clear that issues of Body are again ultimately responsible for the separation experienced. If the body were healthy then there would be no separation from peers and no realization that time to interact with peers and to fit in is limited.

The fourth category in Neuman's model is spiritual stressors. This variable is perhaps the most difficult to evaluate. Few of the participants mentioned God, or church, or faith of any kind, but they all found ways to maintain hope for the future. One way they did this was to refer to themselves as "miracle children" as an indicator that they had exceeded the expectations of their physicians and perhaps could continue to do so. They cautiously discussed potential cures and found ways to distance themselves from the illness. These coping mechanisms are a product of all the stressors in the grounds of Body, Time, and Others. The physical deterioration of the body causes all of the stressors associated with Time and Others, such as shortened life-span and not fitting in, to become salient for these adolescents. These stressors, in turn, bring on the need to cope in a productive way.

The final variable in Neuman's Systems Model is development. Developmentally, the participants are chronically ill adolescents and this presents special issues for them. Their treatments and hospitalizations cause them to be dependent at a time when they are seeking independence. At this time most adolescents face an extended future and feel invulnerable, but the participants have limited time and are extremely vulnerable physically. This is the variable that is most related to the ground of Others. Issues of Body and Time, such as physical symptoms and the acceptance of a shortened life-span,

cause significant differences for these teens in the realm of Others. These differences cause them to not fit in at a developmental stage when it is most important to be the same as others.

Neuman's model considers developmental stage as one variable of the client system, but many studies show that stage of development impacts how children understand their illnesses so this becomes an area that requires further examination. Piaget's theory of cognitive development says that as children grow older they develop more sophisticated understandings of the world. The same is true of their understandings of illness. Adolescence is a time when all of the implications of living with cystic fibrosis become clear. The participants articulated very clearly that they understand the genetic origin of the disease, that treatments will have to continue as long as they live, and that there is currently no cure.

Considering adolescence from the perspective of Erikson's psychosocial theory, it is clear that even the healthy adolescent has many issues to deal with. Adolescents are on a search for identity that involves peer groups, appearance, independence, and a future in which they can be and achieve anything. Harris and Super (1995) say, "Adolescents with CF are no different from other adolescents in terms of concerns about the future, their looks, relationships with the opposite sex, etc. It is also a period of emerging independence, when peer groups can be important" (p. 66). Although it is true that adolescents living with cystic fibrosis are much the same as their healthy counterparts, they also have some special difficulties. Davies and Addington (1973) state, "We have found that this already difficult stage is made more difficult for the CF patient and his family by virtue of the youngster's dependence on some family member for physical therapy and the parents' tendency to be overprotective at a time when independence is so valued" (p. 68). Waddell (1983) points out some other concerns, "Adolescent[s with cystic fibrosis] may fear rejection or hostility from peers, siblings and parents, school teachers and directors of

scouting, swimming, and other recreational activities due to 'being different' or 'being treated differently'" (p. 53). This concern of being different was a major theme for the participants.

Just as Neuman's Systems Model provided a framework for understanding the role of stressors, the thematic structure presents a model for examining the developmental aspects of being an adolescent living with cystic fibrosis. The adolescent stage of development relates mainly to the theme Similarities/Differences across the grounds of Body, Time, and Others. The participants talk about their physical symptoms and how they have to leave class coughing or stop activities because of shortness of breath. In terms of Time, they are different because of their daily schedules, the pace at which they live life, and the amount of time they have left to live. Against the ground of Others, they relate that they are perceived as different by their peers and can be isolated. The interconnectedness of Doing/Stopping emerges when it is considered that part of the reason peers perceive the adolescents to be different is because they must limit activities and interrupt social interactions for treatments. Support is also related because the differences lead to a need for support, and it is the people who do not consider the participants to be different (people with knowledge about cystic fibrosis or other sick children) who often provide this support. It is clear that examples from all of the themes weave together to form the differences that the participants experience.

Being different has several implications for these adolescents. The first is that not fitting in may cause the participants to have self-esteem issues. Self-esteem is an issue for healthy adolescents as it is related to identity. Healthy adolescents measure their self-esteem based on their acceptance by others or the extent to which they fit in, and such measures can be particularly harsh on adolescents living with cystic fibrosis because of their many differences from their peers. Korsch (1973) states, "Not surprisingly, self-esteem is one of the personality features that is often most severely damaged in adolescent

patients with chronic illness" (p. 373). Aside from simply not fitting in, these adolescents must deal with the things that make them different. They have physical symptoms such as coughing and shortness of breath, must undergo treatment and sometimes hospitalizations, have extended absences from school, and must limit social interactions and activities. All of these factors can combine to cause the adolescents emotional strain and to lower their self-esteem.

A particular implication of being different deals with compliance with treatments. Compliance is an especially salient issue during adolescence because this is a time when independence is valued, thus teens often rebel against parental restrictions, doing chores, or authority figures of any kind. For adolescents with cystic fibrosis, however, such rebellions can be dangerous. The adolescents state that the treatments are time-consuming, limit their activities, and limit social interactions. They say that since they would rather be doing something else, they are sometimes noncompliant when they are at a friend's house or if it would cause them to be up very late or very early. Korsch (9173) says:

Adolescents are notorious for their mood swings, disorganized schedules, untidiness and lack of self-discipline. The rigors of many of the treatment regimens required for chronic illness do not allow the exploration and experimentation involved in these traditional adolescent behaviors. Breaking rules and other noncompliant behaviors, typical of many adolescents, may have disastrous consequences when they involve failure to comply with the necessary medical regimen for a severe chronic illness (p. 373).

Compliance is an issue that is particularly emergent in adolescence, as the teens are not only capable of a great deal of self-care but also desire to be independent. It is possible that adolescence is a time when the care plan needs to be reevaluated. Neuman's model involves the client in the care plan and this approach could be useful. The consideration of the adolescent's home, school, and social schedules along with their goals and expectations about treatment could help caregivers devise a treatment schedule that, if perhaps no less

tedious, is more agreeable to the adolescents because they were consulted about the care plan. The ideas that the adolescents can have some control over their illness and that maintaining health will allow them more social interactions are important to convey given their continued dependence on adults and possible isolation from peers. Involving these adolescents as much as possible in their care and giving them as much control as possible can only encourage compliance and raise self-esteem.

A final developmental consideration is how adolescents maintain a sense of self in light of their circumstances. A young child would have a poor understanding of the circumstances and would be expected to cope well if the parents did so. An adult would have had many experiences, and could be expected to understand the situation and to find ways to cope. An adolescent, however, can understand the seriousness of the situation but still must deal with growing up. The added difficulty of coping with dying may be very traumatic. The adolescents in this study used support from friends and family, humor, and denial or distancing from the illness to maintain hope for the future.

Galdston (1973) says:

It is a testimony to the vitality of the human spirit that patients with cystic fibrosis prosper as they do, with as little evidence of psychic disability as they manifest. To achieve this goal, patients must rely heavily upon their capacity to deny the import of facts, either as to their ultimate meaning or as to the emotions which their recognition would evoke. This use of denial allows the patient not to know that which would otherwise impede the conduct of his life. It affords a selective inattention, saying 'yes, but...' to the fact. It enables the patient to register perceptual data without having to acknowledge the significance of those perceptions relative to his hopes for the future (p. 378).

For adolescents, this acceptance of death and the need to not dwell on it is particularly important given that their lives are really just beginning. Allowing themselves to admit openly that an early death is a real possibility would lead to resignation and a loss of hope. In 1988, Hinds and Martin described hope for adolescents living with cancer as the degree

to which an adolescent held a comforting and realistic belief that a positive future exists for himself or herself and others. Also, an earlier study by Hinds (1988) differentiated wishing from hopefulness. "Wishing involved denying the seriousness of the situation, whereas hopefulness was characterized by recognizing the situation as serious or being reality oriented" (Farran, Herth & Popovich, 1995, p.174). The participants' use of distance is not unrealistic. They acknowledge the seriousness of their situation, they just prefer not to discuss it. Their disassociation of "self" from the illness is positive as well. Both strategies allow the adolescents to recognize the reality of their situation without losing hope for the future. It would be important for caregivers to recognize this need for distance from the illness, as pushing them to openly admit to a grim future could cause them to give up hope.

The participants indicate very clearly that they are aware of the seriousness of their situations and the need for treatment. They say that the treatments are time-consuming and separate them from their peers, which leads to noncompliance. The participants relate many concerns about fitting in and developing an identity. They provide examples of how they disassociate from the disease to maintain a sense of self. Finally, because they are aware that the disease is terminal and accept that, they do not directly discuss death in order to maintain hope for the future. These are the most salient developmental considerations for adolescents living with cystic fibrosis.

It is obvious from the data in Chapter IV that whether or not the stressors are labeled according to Neuman's model, they are present and they are plentiful. One important finding of this study, then, is that adolescents living with cystic fibrosis live with an enormous amount of stress. In examining their lines of defense, however, it becomes clear that they find ways to cope that are healthy and mature.

One very important defense for these adolescents is the support they receive from others. Their parents and caregivers help them with treatments and physical care, their

families and communities help with fund-raisers to find a cure, and their families and friends accept them and help to keep humor and laughter in their lives. In addition to support from others, these adolescents contribute to their own defenses by finding healthy ways to cope with the illness. They expressed that they were aware of the seriousness of their situation, but they also exhibited a mature way of dealing with that. The participants discussed the necessity of their treatments, and their acceptance of that, despite the fact that they were seen as restrictive and tedious. They have also found ways to disassociate their "selves" from their bodies and the disease. They refer to their affected bodies in an impersonal way and discuss children who have CF in a general rather than a personal way. This allows them to preserve a sense of "self" that is separate from cystic fibrosis. It is clear that in addition to the physical care that defends them from serious illness, the participants also have extensive external support systems and inner strengths that contribute to their lines of defense.

The Neuman's Systems Model, with its assessment of stressors and defenses, illustrates very clearly that the phenomenological grounds of Body, Time, and Others as well as the themes presented against them are intimately connected. These stressors affect all parts of life and do not stand alone. The coping mechanisms, as products of the stressors, are equally as connected. The strength of Neuman's model as well as of the thematic structure presented here is that they accurately describe the big picture by integrating all the parts of the experience of being an adolescent living with cystic fibrosis. The holistic nature of these models allows an intricate description of the experience to show through in its entirety.

There are several major implications that can be taken from examining the results from the perspective of Neuman's Systems Model. The first is that life is very complex for these adolescents. They live with many different stressors and these have been identified. The participants clearly articulated that areas of particular difficulty were being different

from others, being limited in activities and social interactions by their bodies, and being isolated from and unaccepted by their peers. What was also discovered, however, is that these adolescents are capable of maintaining wellness through utilization of their support systems and personal coping skills. It could be helpful, then, to evaluate the coping mechanisms and support systems of adolescents living with cystic fibrosis to determine the ways in which they may need additional support. Those with strong support systems may do well on their own, while those with weak support systems may require additional help from physicians, social workers, or child life specialists.

The fact that major stressors and coping mechanisms have been identified has meaning for the adolescents and their caregivers. Making caregivers aware of these stressors and coping skills would allow them to be more sensitive in their interactions with these teens. It would give them some sense of what is important to these adolescents and why they react to certain situations in particular ways. Such an increased sensitivity could encourage better communication between adolescents and caregivers that would allow the adolescents to feel better understood and supported. The conclusions drawn from the developmental issues and the role of stressors will now be discussed.

Conclusions

The purpose of this study was to determine the meaning of living with cystic fibrosis for adolescents. They discussed their differences from their peers and their strong desire to be "the same." They talked about having to stop activities because their bodies had failed them. They referred to their concern about their uncertain futures, and they discussed their extensive support systems and illustrated their ability to maintain hope. Their experiences are difficult and frightening and stressful, but their ability to cope on a daily basis is mature and healthy. And aside from all of this, they are dealing with the many "typical" aspects of just growing up.

The numerous stressors, or things these adolescents must cope with, and the importance of support in their lives indicates that family, friends, and other caregivers play a significant role in helping them maintain hope for the future. It is important, then, to consider the ways in which others can provide support and help the participants cope. Carl Rogers (1961) outlines a way of interacting that could aid caregivers in this area.

Rogers (1961) states, "If I can provide a certain type of relationship, the other person will discover within himself the capacity to use that relationship for growth, and change and personal development will occur" (p. 33). Rogers (1961) posits that when a caregiver is open and "real" in the relationship, and understands the feelings of the other and accepts him or her, then the other is free to truly explore his or her experiences and emotions. Rogers (1961) suggests that when the client, or any other, is involved in such a relationship then his or her innate ability to mature and develop will become realized.

This type of relationship has the potential to be especially useful for adolescents living with cystic fibrosis. If their caregivers are "real" in their relationships, and are willing to allow the adolescent some control in the situation, many of the adolescent's growth and development issues can begin to be explored in a psychologically safe environment. The adolescents will feel more at ease to communicate their hopes and fears, will feel more control over their circumstances, and will know they are supported by the people around them in a way that goes beyond simply caring for their bodies. Although building these relationships would not solve all of the adolescents' problems, it would allow them to grow and develop, maintain a sense of hope for the future, and have a safe haven when the reality of their situation becomes especially harsh. This psychologically safe environment where they are completely accepted would allow them to maintain a sense of well-being.

The adolescents identified many stressors that affect them and their coping mechanisms. They discussed how these things affected their development and their search

for independence and identity. In addition to realizing the essence of this experience for the adolescents, it is also necessary for caregivers and families to utilize this information so that the teens receive the most sensitive and effective care possible. The main suggestions for families and caregivers are as follows:

1. Evaluate the adolescent's coping mechanisms and support system. Adolescents who experience a low level of support may need extra attention and understanding from family members and medical personnel in order to raise their self-esteem and maintain an optimal state of wellness.
2. Learn as much as possible about the disease and the adolescent. The adolescents consider knowledgeable people to be accepting and supportive. If caregivers and family members are more sensitive in their interactions, it will promote communication and lead to the adolescent feeling better understood.
3. Involve the adolescent in his or her care plan. Adolescence is a completely different life stage than childhood, and the care plan should reflect that. Involving the adolescents in their own care will raise self-esteem, allow them a locus of control over the illness, and satisfy their growing need for independence.
4. Recognize the stressors and coping strategies used by the adolescents. Caregivers and family members should understand that the teen needs to maintain a sense of self that is separate from the disease and should encourage the teens to develop that "self." They should also recognize that the adolescent's need to avoid discussion of death is a healthy form of denial that helps them maintain hope for the future. In failing to understand these coping strategies, caregivers and families risk causing the adolescent to lose hope.
5. Provide psychologically safe environments for the adolescents. Caregivers and family members need to be "real" in their relationships and should try to be accepting, nonjudgmental, and understanding of the adolescent's experiences and

emotions. This safe environment will allow the teens to deal with developmental issues and feel supported.

Caregivers and family members provide a wealth of support for adolescents living with cystic fibrosis, and these suggestions offer additional ways of giving support. The adolescents can only be helped in their creation of a human experience by caring, knowledgeable supporters.

Limitations Of This Study and Areas for Future Research

Although the themes that were presented in this study were solidly represented across all of the participants' responses, the number of participants was small. If more participants were included, it is possible that additional support for the current thematic structure would be found or that a broader understanding of the situational contexts would be reached. Also, none of the participants was over the age of 16 years, so it is possible that other themes or developmental considerations would emerge for older adolescents and young adults. These limitations do not detract from the very real information gathered in this study, but they do suggest a need for further research.

Additional research would help describe the full range of developmental experiences, and in order to do this it would be necessary to interview older adolescents and young adults living with cystic fibrosis. These studies would help determine if the experience of living with cystic fibrosis changes as the shift is made from being a high school student to the next phase of life. In addition, similar studies involving adolescents living with other chronic illnesses such as cancer, diabetes, or HIV/AIDS would be helpful in determining if experiences are differentiated by illness or if all adolescents living with chronic illnesses have similar experiences. These studies would provide insight into overall stressors of chronic illness for adolescents, their coping abilities, and the role caregivers, family, and friends can play in helping the adolescents to cope.

Other possibilities for use of this research are more quantitative in nature. The stressors and coping mechanisms presented here could be developed into an assessment tool for families and caregivers. Such an assessment could be developed from statements and behaviors associated with each of the themes Similarities/Differences, Doing/Stopping, and Support. For example, verbal expressions of being different from peers or an awareness that the adolescent rarely interacts socially with peers (or seems isolated) would fall under Similarities/Differences. Items for Doing/Stopping could be things such as the adolescent often being interrupted from activities for treatments or being restricted from activities that are potentially dangerous to his or her health. Support items could be evaluating if anyone in the family helps with treatments or if there is someone who brings humor into the adolescent's life.

These factors could also be presented in a workshop for caregivers to show them what these teens are going through and how they can help. Such workshops could include information on the difficulties of adolescence in general and then move on to particular hardships for adolescents living with cystic fibrosis. The three areas of concern, Similarities/Differences, Doing/Stopping, and Support, could be discussed along with the often unspoken issues of an uncertain future and the difficulty of maintaining a sense of self that is separate from the illness. The coping strategies of not directly discussing death and of disassociating the self from the body and illness, in particular, will be essential knowledge for the caregivers so that they may help the adolescents maintain hope for the future.

REFERENCES

REFERENCES

- Barton, K. & Cattell, R. B. (1972). Personality before and after a chronic illness. Journal of Clinical Psychology, 28(4), 464-467.
- Bedell, J. R., Giordani, B., Amour, J., Tavormina, J. & Boll, T. (1977). Life stress and the psychological and medical adjustment of chronically ill children. Journal of Psychosomatic Research, 21, 237-242.
- Bibace, R. & Walsh, M. E. (1980). Development of children's concepts of illness. Pediatrics, 66(6), 912-917.
- Bluebond-Langner, M. (1974). I know, do you? A study of awareness, communications, and coping in terminally ill children. In B. Shoenberg, A. Carr, A. Kutscher, D. Peretz & I. Goldberg (Eds.), Anticipatory grief (pp. 171-181). New York: Columbia University Press.
- Boyle, I. R., di Sant'Agnese, P. A., Sack, S., Millican, F. & Kulczycki, L. L. (1976). Emotional adjustment of adolescents and young adults with cystic fibrosis. Journal of Pediatrics, 88(2), 318-326.
- Boyle, I. R., Sack, S., Millican, F. & di Sant'Agnese, P. A. (1973). Emotional adjustment in adolescents and young adults with cystic fibrosis. In J. A. Mangos & R. C. Talamo (Eds.), Fundamental problems of cystic fibrosis and related diseases (pp. 385-390). New York: Intercontinental Medical Book Corporation.
- Burns, W. J. & Zweig, A. R. (1980). Self-concepts of chronically ill children. Journal of Genetic Psychology, 137, 179-190.
- Burton, L. (1975). The family life of sick children: A study of families coping with chronic childhood disease. London: Routledge & Kegan Paul.
- Campbell, J. D. (1975). Illness is a point of view: The development of children's concepts of illness. Child Development, 46, 92-100.
- Caradang, M. L. A., Folkins, C. H., Hines, P. A. & Steward, M. S. (1979). The role of cognitive level and sibling illness in children's conceptualizations of illness. American Journal of Orthopsychiatry, 49(3), 474-481.
- Davies, M. & Addington, W. (1973). Psychosocial aspects of cystic fibrosis family life as they affect medical management. In P. R. Patterson, C. R. Denning & A. H.

Kutscher (Eds.), Psychosocial aspects of cystic fibrosis: A model for chronic lung disease (pp. 59-70). New York: The Foundation of Thanatology.

Docter, J. M. (1973). The chronically ill child: Soma and psyche. In P. R. Patterson, C. R. Denning & A. H. Kutscher (Eds.), Psychosocial aspects of cystic fibrosis: A model for chronic lung disease (pp. 19-26). New York: The Foundation of Thanatology.

Dooley, R. R. (1973). Management of the terminal adolescent and the family. In P. R. Patterson, C. R. Denning & A. H. Kutscher (Eds.), Psychosocial aspects of cystic fibrosis: A model for chronic lung disease (pp. 71-75). New York: The Foundation of Thanatology.

Drotar, D., Doershuk, C. F., Stern, R. C., Boat, T. F., Boyer, W. & Matthews, L. (1981). Psychosocial functioning of children with cystic fibrosis. Pediatrics, 67(3), 338-343.

Galdston, R. (1973). Growing up with cystic fibrosis. In J. A. Mangos & R. C. Talamo (Eds.), Fundamental problems of cystic fibrosis and related diseases (pp. 377-384). New York: Intercontinental Medical Book Corporation.

Farran, C. J., Herth, K. A. & Popovich, J. M. (1995). Hope and hopelessness: Critical clinical constructs. London: Sage Publications.

Harris, A. & Super, M. (1995). Cystic fibrosis: The facts. (3rd ed.). Oxford: Oxford University Press.

Hinds, P. S. (1988). The relationship of nurses' caring behaviors with hopefulness and health care outcomes in adolescents. Archives of Psychiatric Nursing, 2(1), 21-29.

Hinds, P. S. & Martin, J. (1988). Hopefulness and the self-sustaining process in adolescents with cancer. Nursing Research, 37, 336-340.

Isaacs, J. & McElroy, M. R. (1980). Psychosocial aspects of chronic illness in children. Journal of School Health, 50(5), 318-321.

Korsch, B. M. (1973). Effects of chronic illness on adolescents and young adults. In J. A. Mangos & R. C. Talamo (Eds.), Fundamental problems of cystic fibrosis and related diseases (pp. 371-376). New York: Intercontinental Medical Book Corporation.

Kvale, S. (1983). The qualitative research interview: A phenomenological and a hermeneutical mode of understanding. Journal of Phenomenological Psychology, 14(2), 171-196.

Lowit, I. (1973). Social and psychological consequences of chronic illness in children. Developmental Medicine and Child Neurology, 15(1), 75-77.

Mattsson, A. (1972). Long-term physical illness in childhood: A challenge to psychosocial adaptation. Pediatrics, 50(5), 801-811.

Neuhauser, C., Amsterdam, B., Hines, P. & Steward, M. (1978). Children's concepts of healing: Cognitive development and locus of control factors. American Journal of Orthopsychiatry, 48(2), 335-341.

Neuman, B. (1995). The Neuman systems model (3rd ed.). Norwalk, CT: Appleton & Lange.

Oke, C. & Dewey, D. (1997). Social skills of children with cystic fibrosis and their siblings. Unpublished poster presentation presented at the Society for Research in Child Development conference, Washington, DC.

Patterson, P. R. (1973). Psychosocial aspects of cystic fibrosis. In P. R. Patterson, C. R. Denning & A. H. Kutscher (Eds.), Psychosocial aspects of cystic fibrosis: A model for chronic lung disease (pp. 3-12). New York: The Foundation of Thanatology.

Perrin, E. C. & Gerrity, P. S. (1981). There's a demon in your belly: Children's understanding of illness. Pediatrics, 67(6), 841-849.

Piaget, J. (1929). The child's conception of the world. New York: Harcourt Brace.

Piaget, J. (1930). The origins of intelligence in children. New York: International Universities Press.

Polkinghorne, D. E. (1989). Phenomenological research methods. In R. S. Valle & S. Halling (Eds.), Existential-phenomenological perspectives in psychology (pp. 41-60). New York: Plenum Press.

Pollio, H. R., Henley, T., & Thompson, C. J. (1997). The phenomenology of everyday life. New York: Cambridge University Press.

Richmond, J. B. & Waisman, H. A. (1955). Psychologic aspects of management of children with malignant diseases. American Journal of the Diseases of Children, 89, 42-47.

Rogers, C. (1961). On becoming a person. Boston: Houghton Mifflin Company.

Sohier, R. (1997). Neuman's systems model in nursing practice. In M. R. Alligood & A. Marriner-Tomey (Eds.), Nursing theory: Utilization & application (pp. 109-127). St. Louis: Mosby.

Tavormina, J. B., Kastner, L. S., Slater, P. M. & Watt, S. L. (1976). Chronically ill children: A psychologically and emotionally deviant population? Journal of Abnormal Child Psychology, 4(2), 99-111.

Taylor, S. J. & Bogdan, R. (1984). Introduction to qualitative research methods: The search for meanings. (2nd ed.). New York: John Wiley & Sons.

Thomas, R. M. (1996). Comparing theories of child development. (4th ed.). Pacific Grove: Brooks/Cole Publishing Company.

Thompson, C. J., Locander, W. B., & Pollio, H. R. (1989). Putting consumer experience back into consumer research: The philosophy and method of existential-phenomenology. Journal of Consumer Research, 16, 133-146.

Tropauer, A., Franz, M. N. & Dilgard, V. W. (1970). Psychological aspects of the care of children with cystic fibrosis. American Journal of the Diseases of Children, 119, 424-432.

Waddell, C. (1983). Faith, hope and luck: A sociological study of children growing up with a life-threatening illness. Washington, D. C.: University Press of America, Inc.

Whyte, D. A. (1994). Family nursing: The case of cystic fibrosis. Aldershot: Avebury.

Winder, A. & Medalie, M. (1973). Support for growth in cystic fibrosis teenagers. In P. R. Patterson, C. R. Denning & A. H. Kutscher (Eds.), Psychosocial aspects of cystic fibrosis: A model for chronic lung disease (pp. 103-112). New York: The Foundation of Thanatology.

Wolfish, M. G. & McLean, J. A. (1974). Chronic illness in adolescents. Pediatric Clinics of North America, 21(4), 1043-1049.

APPENDIX

Dear Children's Hospital Patients:

I am writing to you on behalf of Nicole Graham. Nicole is a Child Life Student at the hospital. She is working toward her master's degree in Child Development at The University of Tennessee, Knoxville. The hospital has given her permission to contact you about participating in a research project she is conducting.

Nicole is interested in interviewing adolescents (ages 11-19) who have been diagnosed with cystic fibrosis. She would like to find out about their lives and experiences. She has enclosed further information about the study for you to read. Please return the included postcard to her if you are interested in being contacted about participating in the study.

Sincerely,

Young Lee
Child Life Specialist

Dear Children's Hospital Patients:

My name is Nicole Graham and I am a master's student in Child Development at the University of Tennessee, Knoxville. In addition, I also work at East Tennessee Children's Hospital as a Child Life Student. This is my third semester at the hospital, so some of you may have already met me.

I am contacting you because I would like to ask for your help in a research study that I would like to do. As a Child Life Student, I have become very interested in the lives and experiences of adolescents living with cystic fibrosis. I believe that this group needs to be better understood in order to receive the best care possible. I would like to find out more about adolescents living with cystic fibrosis. This will be the topic of the research for my master's degree.

I would like to interview adolescents (ages 11-19) who have been diagnosed with cystic fibrosis about their experiences. I am particularly interested in academic, social, and emotional experiences. Enclosed you will find consent forms for parents/guardians and for adolescents. These forms provide basic information about the study. If you choose to participate in the study, you will need to bring the signed consent forms to the interview. If you are under 18 years of age, you need to have parental consent to participate in the study. There is a postcard enclosed so that you can let me know if you would like to be contacted about participating in this project.

I am very excited about this project and the information that could come from it. Feel free to contact me if you have any questions about the information you have received:

Nicole Graham
3700 Sutherland Avenue C-8
Knoxville, TN 37919
Phone #(423) 974-5316

Thank you for considering participating in this study.

Sincerely,

Nicole Graham
Child Life Student

Parental Informed Consent for Adolescent Interview

The purpose of this project is to find out what adolescents who have cystic fibrosis think about their lives. The potential benefit of this project may be that it will help families, doctors, nurses, child life specialists, social workers, and others to understand what it is like to be an adolescent living with cystic fibrosis, and that they may then be able to be more aware of the needs of their children/patients. The potential risk of being part of this study is that it does deal with a topic that may cause your child to feel uncomfortable. I expect this to be a positive experience for your child, and every effort will be made to make sure your child is comfortable. A referral to a licensed clinical social worker will be available to your child if necessary.

I will interview your child for about an hour and ask questions about what it is like to be an adolescent who has cystic fibrosis. Before the interview starts, I will also ask your child to fill out a questionnaire about basic information such as age, age at diagnosis, and race. The interviews will take place at a time and place that you, your child, and I all agree on. If any of the questions make your child feel uncomfortable, he or she does not have to answer. Your child's involvement is completely voluntary. He or she may choose to stop being part of the study at any time without penalty.

With your child's permission, the interviews will be tape-recorded and your child can ask to have any part of the tape erased after the interview. All erasures will be done while your child is present. If your child chooses not to have the interview tape-recorded the researcher will take written notes of the interview. The information on the tapes and in written notes will be kept confidential, and nothing that identifies your child will be recorded on them. The information from the interviews will be used in my master's degree thesis, and may be used in presentations at professional conferences and in professional publications. Your child will not be identified in any publications, research reports, or presentations. Written records that identify your child will be kept in a locked filing cabinet separate from the interview data. Only Dr. Tegano (my major professor) and I will have access to identifying information. Members of research groups will help with the data analysis and will sign confidentiality agreements. The data will be destroyed immediately after the study is complete. The results of the study will be made available to you if you sign up on a mailing list that I will have at the time of the interview.

Your child will also be given a choice about participating in the study, and will be asked to sign a form saying that he or she agrees to participate. The only time that confidentiality would be broken is if your child revealed information that might be life-threatening. If you have any questions about this research or your child's rights as a participant, please feel free to contact me, Nicole Graham, or Dr. Deborah Tegano, Child and Family Studies, Jessie Harris Building, The University of Tennessee, Knoxville, 37996-1900, Phone #(423) 974-5316.

I have read the explanation of this project and agree to allow my child to participate.

Child's Name _____

Parent/Guardian Name _____

Signature _____ Date _____

Adolescent's Informed Consent for Interview

The purpose of this project is to find out what adolescents who have cystic fibrosis think about their lives. The potential benefit of this project may be that it will help the people who take care of you, such as doctors and nurses, to understand what it is like to be an adolescent living with cystic fibrosis. If they understand, they may be able to be more aware of the needs of those in a similar situation. The potential risk of being part of this study is that it does deal with a topic that may cause you to feel uncomfortable. I will try to avoid causing you discomfort, and hope that this will be a positive experience. If necessary, a referral will be available to a licensed clinical social worker at East Tennessee Children's Hospital.

I will interview you for about an hour and ask questions about your life and about having cystic fibrosis. Before the interview starts, I will also ask you to give me some information about yourself, such as your age, your age at diagnosis, and your race. The interviews will take place at a time and place that you, your parents/guardians, and I agree on. If any of the questions make you uncomfortable, you do not have to answer them. Your involvement in the study is completely voluntary, and you can stop participating at any time without penalty.

With your permission, the interviews will be tape-recorded and you can have any part of the tape erased after the interview. All erasures will be done in your presence. The information on the tapes will be kept confidential, and nothing that identifies you will be recorded on them. If you do not want to have the interview tape-recorded then I will take notes during the interview. The information on the tapes and in notes will be used in my master's degree thesis, and may be used in professional presentations and publications. You will not be identified in any publication, presentation, or research report. Written records that identify you will be kept in a separate locked filing cabinet from the interview data that only Dr. Tegano (my major professor) and I will have access to. Members of research groups will help analyze the data, but will agree to keep all information confidential. The data will be destroyed immediately after the project is complete. The results will be available to you if you sign up on a mailing list that I will provide at the time of the interview.

If you are under 18 years of age, you are required to have parental consent to participate in this project. The only time that confidentiality may be broken is if you reveal any life-threatening information. If you have any questions about the project or your rights as a participant, please feel free to contact me, Nicole Graham, or Dr. Deborah Tegano, Child and Family Studies, Jessie Harris Building, The University of Tennessee, Knoxville, 37996-1900, Phone #(423) 974-5316.

I have read the explanation of this project and agree to participate.

Name _____

Signature _____ Date _____

I agree to have the interview tape-recorded: Yes _____ No _____

My child and I have read the information about your study and are willing to be contacted about participating.

Please write the adolescent's name, address, and phone number below. Use the envelope provided to return this information to me and I will contact you to discuss participation in the study. Thank you!

Name: _____

Address: _____

Phone: _____

Demographic Questionnaire

Name:

Age:

Race:

Age at diagnosis of cystic fibrosis:

Do you attend public/private school? If not, are you schooled at home?

Are you involved in any activities outside of school work? If so, please list them.

Do you have brothers and sisters? If so, please list their ages and genders.

VITA

Nicole Graham was born in New York. She received a Bachelor of Arts in Spanish in 1992 from Louisiana State University. Following that, she continued her education at The University of Tennessee, Knoxville in the Department of Child and Family Studies. The masters degree was received in December 1998. She is now pursuing a career as a Child Life Specialist.